Embracing Gender Identity in Men with Intellectual Disabilities

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June 2021

Research submitted in partial fulfilment of the requirements for the degree of Doctor in Clinical Psychology (DClinPsy), Royal Holloway, University of London

Acknowledgments

I would like to say a huge thank you to my supervisors, Dr Kate Theodore, and Dr Karen Dodd, for their continued support throughout this process. Their expertise and guidance have been invaluable, and I am incredibly grateful for how approachable, containing, and encouraging they have been. I feel very lucky to have had supervisors with such brilliant attention to detail and clarity of thought.

I would also like to say a huge thank you to John (expert by experience) and Max (co-researcher). The study benefitted profoundly from their input and I am so grateful for the ways in which their insightful perspectives shaped the research process.

To all of the participants who were involved in this project, thank you so much for being so generous with your time and for providing such thought-provoking data. I was inspired by your willingness to share your experiences in order to improve support for others.

A special thanks to my DClinPsy team (Hattie, Katie, and Cecilia) for being such fantastic and supportive companions on this journey. I could not have done this without you. And to the wider cohort, it has been such a privilege to study and work alongside such a lovely group of trainees and colleagues.

Finally, thank you to my amazing family and friends for being there for me so consistently. To Amy for the IT and formatting coaching sessions, to my Mum and Dad for backing me in all my ambitions, and to Daisy and my lovely husband Nik for always believing in me and being patient when I doubt myself.

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Lay Summary

Why did we do this research?

This research took place at Royal Holloway, University of London. This research is about the gender identity of men with learning disabilities. 'Gender identity' is how we think and feel about our gender (feeling like a man or a woman or other gender).

The gender of people with learning disabilities is not thought about enough. They are often not treated as "real" men and women. This can damage well-being. We wanted to find out more about how people with learning disabilities understand their gender identity, and how this is supported by staff.

What did we do?

There were two main parts to this research.

Part 1: Systematic Review

- First, we looked in online libraries and found all the research that has already looked at how people with learning disabilities understand their gender identity, and how this is supported by staff. This is called a 'systematic review'.
- We looked for themes from all of this research.

What the Systematic Review Found

We found 23 research papers. The main things they found were:

People with learning disabilities found their gender identity difficult to understand. Things that made learning about gender identity hard were:

1. **Not having a lot of independence:**
    - People with learning disabilities need support from other people. They often do not have much independence.
    - People can be overprotective of people with learning disabilities and treat them like children.
    - A lot of the time people with learning disabilities do not have jobs and do not become parents. This can stop them feeling like adults.
2. **Not enough chance to learn about identity:**
    - People with learning disabilities do not have a lot of opportunities to talk about their identities.
    - They do not have enough information or role models to help them learn about gender identity.
3. **The learning disability identity:**
    - People with learning disabilities are not seen as "real" men and women. Other people think more about their learning disability than their gender.
    - People with learning disabilities want to be "normal" and "fit in". This can stop them from showing who they truly want to be.
4. **Stereotypes:**
    - There are gender stereotypes in support services. This means that staff guess that men only like activities that are more manly, and women only like activities and things that are more 'girly'. A lot of the time these guesses can be wrong because everyone is different.

Part 2: Research Study

- Most support workers in learning disability services are women. This means it can be difficult for men to learn about being a man.
- We wanted to find out what 'being a man' means to men with learning disabilities and what support they need with this.
- We spoke to five men with learning disabilities and asked them to tell us their own story. We also spoke to their five support workers. This type of research is called qualitative research.
- We asked what the men with learning disabilities think and feel about being a man. We also asked what is helpful and unhelpful in supporting men with their gender identities.

What the Research Study Found

Three main themes were found from the interviews:

1. **Understanding gender and identity:**
    - All of the men with learning disabilities liked being a man and said that being a man was important to them.
    - The men did not talk about learning disability in their interviews. They said they were capable and independent. They thought that these things are important for men.
    - Support workers can think more about disability than being a man when they support men with learning disabilities.
2. **Things that made learning about identity difficult:**
    - Support services help people more with daily living skills than helping people with friends and relationships.

- Support workers do not have enough time to build trust with service users. This makes it difficult to have private conversations that help service users to learn about their identities.
- People can have negative beliefs about people with learning disabilities because they are seen as 'different' from others. Support workers were worried about this. They wanted to help the men to be whoever they wanted to be, but also wanted to help them to "fit in" with the crowd.
- There are not many male support staff. This means that men with learning disabilities cannot always choose to have support from a man when they would like it.

3. **Things that helped with learning about gender identity:**
    - Service users need to trust staff if they are going to talk and learn about their identities.
    - Service users need support with friends and relationships.
    - Service users need support to try lots of different activities to see what they are interested in.
    - Service users need support to make their own choices and be more independent. They should be able to choose between different staff for support with different things.

What Next?

We will publish the research and make sure that lots of different groups of people know what the research found.

To make support for people with learning disabilities better:

- Services need policies about how to help people learn about gender identity.

- Service managers should make sure there are good relationships between staff and service users.
- Men with learning disabilities need more support with social relationships. Support groups would be helpful for meeting different people.
- Service managers should try to hire more men.
- Support staff need training about sensitive conversations with men with learning disabilities.
- We need to support people with learning disabilities as people, not just thinking about their learning disability. We need to help staff to notice and think about gender stereotypes.
- We need to help men with learning disabilities to be independent and make their own decisions. More advocacy services would help service users to speak for themselves.
- Services should ask for regular feedback from service users.

Paper 1

Embracing Gender Identity in People with Intellectual Disabilities

Systematic Review

Abstract

This paper aimed to systematically review and synthesise qualitative and quantitative studies exploring how people with intellectual disabilities (ID) understand their gender identity, and how this is facilitated by their support staff. Given the influence that gender has on health outcomes, and the significant health inequalities faced by people with ID, it is disappointing that gender has been largely ignored in practice, policy, and research related to the ID population. Government initiatives emphasise that people with ID should be supported to develop valued social identities through inclusion in all aspects of community life and the realization of normalised aspirations. However, in practice, support for culturally valued masculine and feminine social roles is not emphasised. The need for a review to explore the experiences and support needs of the ID population was therefore indicated, to start to close this gap between policy and practice and inform service provision. Three key databases were searched using relevant search terms. Twenty-three studies met the inclusion criteria, with a total of 587 participants with ID and 42 support staff. Studies were critically appraised using different quality appraisal tools, depending on the study design. The lower overall quality of the quantitative compared to qualitative research in the review was notable. Thematic synthesis (Thomas & Harden, 2008) was employed to synthesise the findings of the 17 included qualitative studies. Narrative synthesis was used to compare findings across the six quantitative/mixed-methods studies. The thematic synthesis generated three master themes: (1) Understanding of self-identity, (2) Barriers to understanding/developing gender identity, (3) Recommendations for practice. The review highlighted the need for support workers to adopt a proactive and collaborative approach to supporting services users with developing their gender identity, including promoting

independence and support with social relationships. Clinical implications, strengths and limitations of the research, and suggestions for future research are discussed.

Keywords: systematic review, intellectual disabilities, learning disabilities, gender identity

Introduction

Human differentiation by gender is a fundamental phenomenon impacting almost every aspect of daily life (Bussey & Bandura, 1999). Sex is biologically determined, however, a person may not identify with the sex they were assigned at birth (ONS, 2019; Reed et al., 2009). Gender identity is a personal deeply felt sense of oneself as being male or female (Nakkeeran & Nakkeeran, 2018; ONS, 2019). It is now recognised that gender is influential for quality of life and is one of the most important social determinants of health (Evans et al., 2011).

Several major theories have been proposed over time to describe gender development, and general consensus is that stereotypical gendered roles are more influenced by culture than inborn biological characteristics (Bussey & Bandura, 1999). The important role of social interactions, cultural expectations and practices, and societal structure is now accepted (Nakkeeran & Nakkeeran, 2018). People with intellectual disabilities (ID) may face challenges due to dependence on others for support to explore their identities and insufficient social opportunities (Clements et al., 1995; Parkes et al., 2009).

Little is known about the self-concept of people with ID, due to a focus on disability over and above other personal factors such as gender (O'Shea & Frawley, 2020; Thompson et al., 2001). Given the influence that gender has on health outcomes (Courtenay, 2000), and the significant health inequalities faced by people with ID (Emerson et al., 2012), it is disappointing that gender has been largely ignored in practice, policy, and research related to the ID population. Historically, people with ID have been considered less than fully-gendered adults (Clements et al., 1995). They are either infantilised and considered asexual; or perceived as hypersexual "animals"

with little control over their sexual urges (Clements et al., 1995; Noonan & Gomez, 2011; Thompson et al., 2001). Their gender is often ignored until it is perceived as a "problem", for example, due to risk associated with sexuality (Burns, 1993). Research has suggested that support systems may contribute to the maintenance of the myth that people with ID are genderless objects, rather than men and women with individual needs and preferences, and support for normative and culturally valued masculine and feminine social roles may not be emphasised (Thompson, 2014; Umb-Carlsson & Sonnander, 2006). On the occasions when people with ID are accepted as sexual/gendered beings, this view is restricted by conformity to the mainstream and heteronormativity (Noonan & Gomez, 2011; Thompson et al., 2001; Wilson et al., 2018). However, research has shown that people with ID experience a wide range of gender identities like those in the non-learning-disabled population (McCann et al., 2016; Parkes & Hall, 2006; Parkes et al., 2009).

Gender is at the core of how society is organised, and we are all evaluated socially in terms of how well we "do gender" (Risman, 2018). Government initiatives such as the 'Valuing People Now' strategy emphasise that people with ID should be supported to develop valued social identities through inclusion in all aspects of community life and the realization of normalised aspirations (Department of Health, 2009). However, this policy fails to acknowledge the gendered identity of people with ID (Charnock, 2013). Considering the crucial influence that gendered identity has on the lives of men and women, gender blindness may hinder the actualization of the four guiding principles of this social policy (Rights; Independent living; Control; Inclusion) (Charnock, 2013).

The body of research on the development of sexual identity in people with ID is growing (Pariseau-Legault & Holmes, 2017; Whittle & Butler, 2018; Wilkinson et al., 2015), and sexuality has been highlighted as a key target area for improving support (Department of Health, 2009). However, there is a dearth of research on gender identity and guidance on how gender disorders should be managed and treated within this population (McCann et al., 2016; Thompson, 2014; Wilson et al., 2018; Wood & Halder, 2014). The limited research on the relationship between disability and gender has typically focused on physical impairment (Gerschick, 2000; Nakkeeran & Nakkeeran, 2018), or has focused on 'disability' as a homogeneous category without acknowledging different types of impairment (Cheng, 2009; King et al., 2020; Shuttleworth et al., 2012). Reviews conducted around the intersection of ID and gender have focused on people who identify as LGBTQ (McCann et al., 2016; Wilson et al., 2018), or on gender 'disorders' within the ID population (Wood & Halder, 2014). The limited existing research in this area has highlighted significant gaps in the understanding of the needs of people with ID (McCann et al., 2016). Researchers have suggested that developing coherent models of gender identity within the ID population would help to shape support (Wilkinson, 2013).

This mixed-methods systematic review aimed to explore existing research around how people with ID understand their biological gender, and how this is or is not supported by the staff that support them. The aim is to conduct a broad search of the literature to investigate how people with ID understand their gender identities, including cisgender identities, rather than the specific focus on gender 'disorders', or 'norm-breaking'/LGBT identities in the existing literature. This review will enable insight into how support staff view and enact their roles in facilitating the

development of gender identity among the people they support, generating knowledge around how ID services can improve support with gender-related issues. It may also facilitate evaluation of existing theory relating to the development of gender identity that have not yet been applied to the ID population. Furthermore, a review of the current evidence base for this under-researched area could help to guide the focus and methodology of future studies in the field.

Method

Literature Search Strategy

"Scopus", "PsycINFO", and "Web of Science" databases were searched in August 2020. Search terms for the categories (namely intellectual disability and gender identity) are listed in Appendix A. The categories of search terms were combined using the Boolean/phrase search mode. Searches were limited to peer reviewed articles published in English. Reference lists of included studies were manually searched for relevant papers. No date restrictions were applied to the search.

Study Eligibility

Inclusion and exclusion criteria (summarised in Table 1) were applied to identify relevant studies.

Studies that investigate gender identity within the Autistic Spectrum Condition (ASC) population, without also including distinct data related to the ID population, were excluded. There is more available research on gender identity within the ASC compared to the ID population, and the intention was to focus exclusively on the ID population.

Table 1

Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Published in English language	Non-English language
Presents the results of peer reviewed research	Non-peer reviewed research (for example, theses/dissertations, conference papers)
Uses either quantitative or qualitative methodologies (including mixed-method study designs and case studies)	Literature reviews Commentary/discussion papers
Sample includes participants of any age/gender/nationality with a diagnosis of ID, and/or their paid staff (including any support staff or healthcare professionals)	Sample includes participants without an ID diagnosis Sample includes the family members of people with ID but not paid support staff
Sample includes people with all severities of ID including borderline, mild, moderate, severe, and profound	Investigates gender identity within the ASC population, without also including distinct data related to the ID population
	Primary topic of sexuality with no data related to gender identity
	Primary topic of self-identity with no data related to gender identity

Study Selection Process

Electronic references were exported to the bibliographic software EndNote X9. Duplicate citations were deleted using Endnote X9 and by hand. Articles were screened following PRISMA's ('Preferred Reporting Items for Systematic Reviews and Meta-Analyses') guidelines (Moher et al., 2009). (See Figure 1 for a PRISMA flow diagram of the study selection process). The primary researcher screened all titles and abstracts to assess eligibility for inclusion in the review. Full text articles for the remaining 87 references were retrieved and inclusion/exclusion criteria were applied. An audit trail of decisions to exclude studies at each stage of the review was recorded using Microsoft Excel spreadsheets. All articles considered to be potentially

eligible were discussed with a second reviewer (the primary researcher's academic supervisor), leading to the exclusion of 13 additional articles.

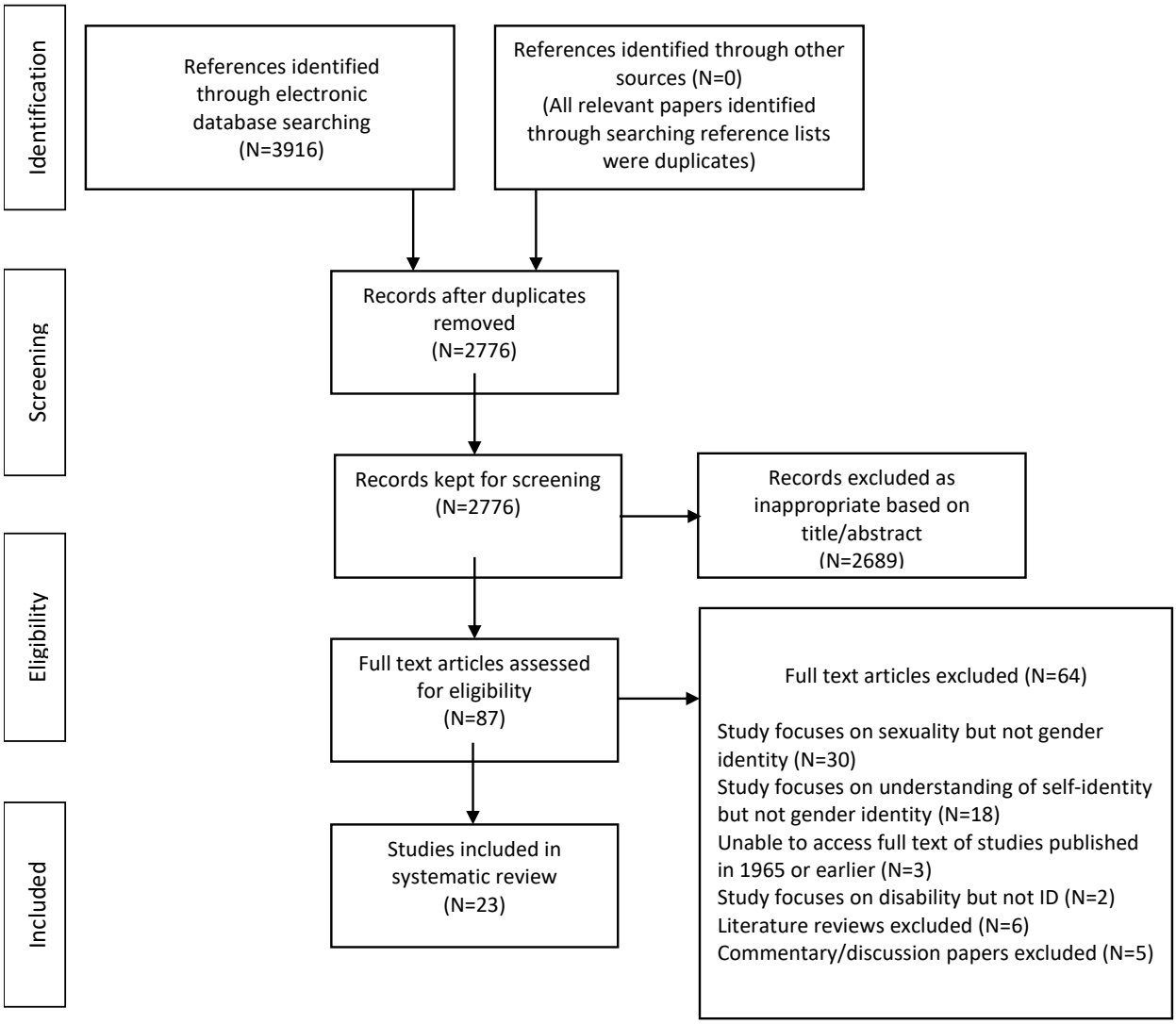

Figure 1: Flow diagram of systematic literature search process

Quality Appraisal

The appropriate quality appraisal tool was applied by study type. The tools used for different study designs are shown in Table 2.

Table 2

Quality Appraisal Tools

Study design	Quality appraisal tool
Qualitative	Critical Appraisals Skills Programme (CASP) checklist for qualitative research (CASP, 2021)
Quantitative	Joanna Briggs (JBI) critical appraisal tools: ▪ Analytical cross-sectional studies tool (Moola et al., 2020) ▪ Quasi-experimental studies tool (Tufanaru et al., 2020) ▪ Case series tool (Munn et al., 2020)
Mixed Methods	Mixed Methods Appraisal Tool (MMAT) (Pluye et al., 2011)

The quality appraisal tools used do not suggest that a scoring system, where total ratings are assigned to the overall quality of each study, is more informative than a descriptive summary using the quality criteria. Considering the limitations associated with critical appraisal (Carroll & Booth, 2015; Dixon-Woods et al., 2006; Dixon-Woods et al., 2007), the aim was not to exclude studies from the review. Rather, the aim was to inform the reader's understanding of the data synthesis and review conclusions, as higher quality research tends to contribute most to the overall synthesis (Thomas & Harden, 2008).

Twenty five percent (n=6) of articles were randomly selected and assessed by a second reviewer independently. Minor discrepancies in ratings were resolved through discussion.

Data Synthesis

Thomas and Harden's (2008) inductive thematic synthesis method was used to synthesise the qualitative research, involving the following stages:

1. Line-by-line coding of findings from primary studies:

QSR's NVivo 11 qualitative data analysis software was used to code Results sections and author interpretations from included studies. Each line of text was coded according to its content and meaning, with new codes being developed inductively.

2. Organisation of coded data into 'data-driven' descriptive themes:

Codes were constantly compared, developed, and grouped into descriptive themes. This involved the qualitative synthesis process of 'translation' (Britten et al., 2002; Fisher et al., 2006), where overarching concepts are identified that capture similarities across studies. At this stage, a framework matrix was created in NVivo, summarising the findings of included studies according to the descriptive themes.

3. Generating analytical themes:

The descriptive thematic framework was reorganised in collaboration with a second reviewer (the academic supervisor) to develop more analytical themes that answer the review question. This stage involved going beyond the primary study findings to generate additional understandings that directly address the review questions. A new analytical thematic framework emerged that sufficiently described all the initial descriptive themes.

Due to the small number of quantitative/mixed-methods studies (with wide-ranging research questions) included in the review, narrative synthesis was used to compare and contrast findings across the studies (Popay et al., 2006). Where possible, studies were grouped according to study design within the textual description.

Findings

Quality Assessment

All but one of the included qualitative studies clearly stated their research aims and appropriately chose to use qualitative methodology. Four of the seventeen qualitative studies met all CASP criteria, with two lower quality studies meeting under half of the criteria. The primary reasons for studies not meeting quality criteria were lack of detail regarding the recruitment strategy; insufficient description of the analysis process; unclear presentation of findings and without discussion of credibility; lack of researcher reflexivity. Appendix B shows all individual quality ratings for each qualitative study.

The one mixed-methods study (Bedard et al., 2010) included in the review was rated as low quality using the MMAT quality appraisal tool. The researchers presented a case study alongside quantitative data to aid understanding of transgenderism and give voice to the ID population. It was deemed that the rationale for using a mixed-methods design was appropriate; however, the case study was not presented in sufficient detail and the quantitative and qualitative study components were not adequately integrated and interpreted.

Only one of the five included quantitative studies met over half of the criteria on the JBI quality appraisal tool. Due to the variety of included study designs and JBI quality appraisal tools used, the primary reasons for not meeting criteria cannot be

meaningfully summarised. Appendix C shows all quality ratings for the included quantitative and mixed-methods research.

Study Characteristics

Across the 23 studies, 21 studies collected data from 587 participants with ID (146 of these were from one quantitative study); and three studies collected data from 42 paid staff supporting people with ID. One of the three studies involving staff participants also included service user participants and reported the findings separately.

The majority of studies reported data on adults (18+) with ID. Three studies reported data on 219 children with ID. Three studies included participants with age ranges spanning adolescence and adulthood (14 – 42 years) (Mutua & Swadener, 2015; Toft et al., 2019; Wheeler, 2007). Of the 587 participants with ID included in the review, 231 were female and 299 were male. One study did not report the gender composition of participants with ID (Toft et al., 2019). Fourteen of the 587 participants with ID had a diagnosis of Down syndrome (Brown et al., 2010; Groves et al., 2018).

One of the three studies reporting data from staff participants did not report the gender composition of the sample (Midjo & Aune, 2018). Across the other two studies, six staff participants were male and 31 were female. Only one study involving staff participants reported the sample age range (18-60 years). One study included paid carers working in ID group homes; one study involved a range of multidisciplinary professionals working in habilitation centres; and the third study recruited staff involved in the transition process from child to adult ID services.

Seventeen of the 23 included studies employed qualitative study designs; five studies used quantitative designs; and one used a mixed-methods design. The mixed-methods study presented a qualitative case study alongside quantitative data; however, qualitative data was not analysed and therefore not included in the thematic synthesis. The majority of qualitative studies collected data using interviews; however other methods such as focus groups and observations were also used. Some studies used participatory methods to complement interviews, such as vignettes and Photovoice methods. Qualitative researchers most commonly used thematic analysis (N=8), followed by interpretative phenomenological analysis (IPA; N=2), narrative analysis methods (N=2), and grounded theory/constant comparative methods (N=2). Three studies did not explicitly specify the type of analysis used. Just under half of the studies did not intend to research gender identity as their primary aim. Some studies aimed to research self-identity more broadly, and several studies were researching sexuality or sexual identity as their primary aim.

Participants with ID were recruited from a range of specialist ID services, including special education schools/colleges; group homes/supported living services; community ID teams in the NHS; self-advocate and support groups; and clinical health services. Some studies recruited from several settings and others recruited all participants from the same service. Studies were most commonly conducted in the UK (N= 11), although also included research in Sweden, the U.S., Australia, Iceland, Canada, Norway and Japan.

Table 3: *Study Characteristics*

Author, year, country	**Research question/aim**	**Design**	**Participants**	**Findings in relation to gender identity**
Abelson & Paluszny (1978) U.S.	To explore age of attainment of gender identity (defined as the ability of a child to identify himself/herself as a boy or a girl) in children with ID compared to neuro-typical children.	Quantitative, quasi-experimental design	Sample: N = 52 children with ID, 36 neuro-typical children. Gender: 26 boys, 26 girls. Age: Mean = 5 years 8 months, range = 3 years 1 month to 10 years 6 months. Setting: Special education school.	In the neuro-typical group, attainment of gender identity was significantly correlated with both age ($r(34) = .5689$, $p < .01$) and IQ ($r(34) = .5014$, $p < .01$). In the ID group, attainment of gender identity was significantly correlated with IQ ($r(50) = .4437$, $p < .01$) but not with age. No gender differences in attainment of gender identity found in either group.
Barron (2002) Sweden	To understand the everyday lives of women with ID and how they view themselves.	Qualitative, interviews and observations	Sample: N = 10. Gender: Female. Age: Range = 21 - 71. Setting: Group homes/communal services.	Participants enjoyed talking about womanhood, although found this difficult. They mostly referred to biological aspects such as menstruation. Participants believed that a "good woman" can manage some daily living tasks independently and is good-looking.

				Participants had internalised a view of themselves as unsuitable for motherhood.
Bedard, Zhang, & Zucker (2010) U.S.	To survey and compare the different gender identities and sexual orientations of people with ID, and examine differences in other diagnoses (for example, schizophrenia, Autism, personality disorder).	Mixed-methods, descriptive design	Sample: N = 32. Gender: 16 males, 16 females. Age: 18+ (mean = 39 years, range = 20 to 64). Setting: Clinical services for emotional/psychiatric difficulties.	Four subjects (12.9%) had gender identity dysphoria (GID). Of those four subjects, three had no additional diagnosis and one had been previously diagnosed with an anxiety disorder. None of the four subjects with GID had a diagnosis of Autism.
Björnsdóttir, Stefánsdóttir, & Stefánsdóttir (2017) Iceland	To explore the manifestation of masculinity, femininity, and autonomy in the lives of Icelanders with ID.	Qualitative, interviews, focus groups, and observations	Sample: N = 44. Gender: Interviews/focus groups with 19 females and 10 males. Observations with 15 individuals with severe or profound ID. Age: Range = 26–66. Setting: A wide range of geographic locations across Iceland.	Men and women relied equally on traditional gender roles in their narratives. Men and women struggled to demonstrate their autonomy. Participants were not involved in everyday decision-making (particularly female participants) and lacked access to adult roles such as employment. Men felt that being able to provide for a family indicates manhood.

Björnsdóttir & Stefánsdóttir (2020) Iceland	To explore how the sexuality of people with severe/profound ID is shaped by socio-cultural sexual scripts and support.	Qualitative, observations	Sample: N = 25. Gender: 13 males, 12 females. Age: Range = 26-66 years. Setting: Assisted living/group homes.	Reduced opportunity to make decisions (for example, about clothing or leisure activities) can reduce opportunities for developing gender identity. Limited access to resources to draw on when forming own sexual scripts. "Suspended childhood" impedes opportunities for performing masculinity.
Brown, Dodd, & Vetere (2010) UK	To explore the life stories and self-concepts of people with Down's syndrome.	Qualitative, interviews	Sample: N = 6. Gender: 5 males, 1 female. Age: 50+ (mean = 53, range = 50–56). Setting: Local NHS Trust.	No participants identified with having Down's syndrome or ID. Rather, participants drew on gendered identities in their narratives and positioned themselves in line with masculine or feminine stereotypes.
Burns & Davies (2011) UK	To examine the relationship between stereotypical gender role beliefs and attitudes towards homosexuality among women with ID.	Quantitative, cross-sectional analytical design	Sample: N = 27. Gender: Female. Age: 18+ (mean = 40.8 years, range 23–65) Setting: NHS Trusts.	The women held very traditional views of gender roles. Stereotypical gender role beliefs were strongly associated with more negative attitudes towards homosexuality ($r = 0.42$, $P = 0.03$).

Charnock & Standen (2013) UK	To explore how video-gaming may offer a space for gendered practice in the lives of boys with ID.	Qualitative, observations and group and individual interviews	Sample: N = 21. Gender: Males. Age: Range = 13-17 years. Setting: Special Education School.	Participants were eager to talk about boyhood and were careful not to allow ID to dominate their accounts of masculinity. Boys used games as an opportunity for identity construction. Gaming allowed the boys to explore masculinity and autonomy without the complication of disability.
Elderton, Clarke, Jones, & Stacey (2014) UK	To support people with ID who identify as LGBT to form positive self-identities through four narrative therapy workshops.	Qualitative, describing and evaluating a support group	Sample: N = 11. Gender: 10 males, 1 female. Age: Range = 28-71. Setting: Community ID Service.	The workshops were experienced positively and helped participants develop richer and more positive self-identities. Workshops helped participants feel more connected to one another and had a positive impact on support workers' practice.
Fitzgerald & Withers, (2013) UK	To explore the sexual identities of women with ID.	Qualitative, interviews	Sample: N = 10. Gender: Female. Age: Range = 19-64. Setting: Community ID services.	Most women had no clear sense of identity and did not view themselves as sexual beings. Participants referred to biological aspects such as body parts and menstruation when asked about womanhood.

				The women held stereotypical views about gender and perceived men to be superior to women. Activities provided at day centres strongly reinforced gender stereotypes.
Groves, Rayner, & Muncer (2018) UK	To understand how the experiences of women with Down's syndrome have impacted on their identities.	Qualitative, interviews	Sample: N = 8. Gender: Female. Age: Mean = 35 years, range = 21–49 years. Setting: Community ID Teams in the NHS.	For many participants, defining womanhood was difficult and they had stereotypical views. Participants lacked autonomy and their identity was heavily influenced by the opinions of others. Participants had a strong desire to be "normal" and assumed they were an unvalued population.
Kifune (1990) Japan	To investigate the effect of sex, age, and IQ on sex-identification among children with ID, comparing the findings against previous research with neuro-typical children.	Quantitative, quasi-experimental design	Sample: N = 146. Gender: 91 boys, 55 girls. Age: Mean = 12 years 4 months, range = 5 years 11 months to 18 years 5 months.	Boys and girls with ID drew a self-sex figure first significantly less frequently than neuro-typical boys (CR = 5.12, $p < .05$) and girls (CR = 11.33, $p < .01$). Age, gender, and severity of ID did not determine whether participants drew a same-sex figure first or not.

			Setting: Special education schools	
Midjo & Aune (2018) Norway	To explore the self-constructions of young adults with ID and the experience of professionals supporting service users to transition to adult ID services.	Qualitative, interviews	Sample: N = 4 participants with ID, 5 professionals. Gender: 2 males, 2 females. Age: Range = 18-24 years. Setting: A habilitation institution. (These services offer tailored healthcare to people with disabilities)	Masked power in caring work restricts the influence that young people with ID have over their identity development and expression. Females constructed themselves as competent and involved in housework. Males expressed a lack of interest in housework and did not mind relying on others for this.
Mutua & Swadener (2015) U.S.	To explore the social construction of gender and sexuality from the standpoint of adolescents with ID, and how disability functions differently among males versus females during adolescence.	Qualitative, interviews	Sample: N = 7. Gender: 4 males, 3 females. Age: Mean =18.9 years, range = 14–21 years). Setting: Special Education Schools or transition programmes.	Socio-cultural expectations and reliance on support limit spaces where adolescents with ID can explore their gendered identities. Participants struggled to talk about their recreational preferences, demonstrating a lack of autonomy in making these lifestyle choices.

				Overprotection limited females' attempts to construct themselves as gendered beings.
O'Shea & Frawley (2020) Australia	To understand how gender appears in the lives of women with ID.	Qualitative, participants co-constructed written stories about their lives	Sample: N = 6. Gender: Female. Age: Range 18-30 years. Setting: ID service.	Gender discourses informed women's stories about their lives. Participants asserted their femininity through traditional feminine roles to resist the ID identity. The women positioned themselves within romantic love discourses to be seen by others as lovable and capable.
Parkes, Hall, & Wilson (2009) UK	To describe the characteristics, presentation, and treatment of people with ID who cross-dress or have gender dysphoria.	Quantitative, case series design (retrospective review of clinical records)	Sample: N= 13. Gender: 12 biological males, 1 female. Age: Mean = 37.5, range = 24 – 62. Setting: Specialist service for people with ID who have additional needs related to their sexuality.	A range of gender identities comparable to the general population was found in the sample. A high level of mental health problems and reported childhood abuse were found among participants. Two people had capacity issues. Reasons for cross-dressing included discomfort about being gay, sexual motivation, wanting to be the opposite

				sex, wanting to be someone else, escaping trauma.
Sommarö, Andersson, & Skagerström (2020) Sweden	To explore attitudes of healthcare professionals towards patients with ID and norm-breaking gender and/or sexual identities. Secondly, to explore the work done to develop LGBTQ-affirmative practice.	Qualitative, focus groups	Sample: N = 19. Gender: 3 males, 16 females. Age: Unknown. Setting: Habilitation centres.	Discussing gender issues was not part of routine practice and most did not address this topic. Unconscious heteronormative bias was found. Barriers to an inclusive treatment approach included lack of training and guidance, lack of inclusive and accessible work material, and concern about offending patients or parents. Participants perceived that disability is a barrier to expressing gender identity. Open questions, awareness of own prejudices, undergoing training, and appointing an LGBTQ representative within services were identified as ways to improve practice.
Tallentire, Smith, David, Roberts, Morrow, Withers, & Smith (2020)	To explore people's experiences of attending an LGBT support group in a secure ID service.	Qualitative, interviews and written information	Sample: N = 18. Gender: 17 males, 1 female. Age: Range = 24-58.	The media and perceptions of the attitudes of others affected decisions about attending the group.

UK			Setting: Secure hospital.	Attitudes of facilitators were important for creating a safe space. The group led to positive emotional change and pride in identity. Meeting people with diverse LGBT identities and hearing about others' experiences was important for group members' confidence.
Toft, Franklin, & Langley (2019) UK	To explore how LGBT+ people with ID understand, negotiate, and enact their sexuality/gender identities.	Qualitative, interviews supported by participatory activities such as vignettes	Sample: N = 13. Gender: Unknown. Age: Range = 16-25. Setting: An LGBTQ youth group and a specialist disability college.	Disability and infantilisation were barriers to exploring and expressing gender identity. Participants struggled to 'prove' themselves as competent individuals who identify as LGBTQ. Many young people hid their gender identity for fear of rejection/discrimination. Young people valued meeting others with similar experiences at support groups.
Umb-Carlsson & Sonnander (2006) UK	To explore gender differences in the living conditions of people with ID	Quantitative, cross-sectional analytical design	Sample: N = 110. Gender: 67 males, 43 females.	Beyond type of employment (which was stereotypically gendered in both the ID and general populations) there were

	and compare the results with the general population.		Age: Women (mean = 34.5, range = 27-41). Men (mean = 35.1, range = 27-42). Setting: Specialist ID services.	significantly fewer gender differences in living conditions within the ID population compared to the general population.
Wheeler (2007) Wales	To explore how men with ID experience their sexual identity.	Qualitative, interviews	Sample: N = 12. Gender: Males. Age: Mean = 25 years 6 months, range = 16-42. Setting: Self-advocacy organisations.	Participants focused more on their differences from than similarities to non-disabled men. They did not live independently or have paid jobs and did not make independent choices due to restrictions placed on them by carers. Participants did not feel that it would be possible for them to become parents. Participants had a desire to conform to the socio-cultural 'ideal male body'.
Wilson, Stancliffe, Parmenter, & Shuttleworth (2011) Australia	To explore the sexual health needs of males with ID, and to determine the role that staff gender plays in responding to these needs.	Qualitative, interviews	Sample: 18 paid caregivers. Gender: 3 males, 15 females. Age: Range = 18-60 years.	ID services are feminine workplaces. Female staff adopt gender-specific boundaries with men with ID. Female staff felt less comfortable regarding male sexual health issues.

			Setting: Group homes.	It is important that men with ID can spend time recreationally with male staff. Male service users look up to male staff members. Male bonding (particularly with staff of a similar age to them) contributes to a valued sense of masculinity.
Wilton & Schormans (2020) Canada	To explore how men with ID imagine and enact masculinity in domestic settings and public places.	Qualitative, mobile interviews (participants led researchers on trips through the city)	Sample: N = 12. Gender: 8 males, 4 females. Age: Range = early 20s to late 50s. Setting: Self-advocate groups and community organisations.	Pervasive paternalism impedes efforts to create an adult identity. The men strove to enact a normative heterosexual masculinity to resist the ID identity, hindering opportunities to explore other forms of disabled masculinity. Men who lived in group homes experienced care as overly controlling and felt they were deprived of self-determination. Men who were in paid employment did not report a lack of autonomy in their lives, despite not living independently.

Thematic Synthesis Findings

Four master themes comprised of eight sub-themes were developed from the thematic synthesis and are shown in Table 4.

Table 4: *Master and Subordinate Themes*

Theme	Sub-themes	Number of contributing papers
1. **Understanding of self-identity**	1. Understanding of gender identity	9
	2. Sexual identity	8
2. **Barriers to understanding/developing gender identity**	1. Barriers to autonomy	14
	2. Lack of opportunity to explore identity	13
	3. Competing identities	12
	4. Gender normativity	12
3. **Recommendations for practice**	1. Opportunities to develop identity	9
	2. Promoting autonomy	11

Theme 1: Understanding of Self-Identity

This theme describes how individuals with ID understand their gender and sexual identities, and how this understanding is shaped by gender stereotypes and socio-cultural views about disability.

1.1 Understanding of Gender Identity. Findings highlighted that it was difficult for both male and female participants with ID to articulate their identities and they relied on gender stereotypes in their narratives. Some female participants referred to biological aspects, such as menstruation, when describing womanhood:

> Can you tell me anything good about being a woman?
>
> L: It's your life, it's, you know, you were born as a woman you can't change that. I know you have sex with a man 'cos you're a woman and you have different parts to your body. You can't stop that. (Fitzgerald & Withers, 2013, p.7)

Others drew on stereotypical norms around gendered appearance and clothing when defining femininity:

> Yeah I think women like dressing up all gorgeous, do the make-up and hair and like picking out nice things like skirts to make them look dressy and gorgeous to impress the men. (Groves et al., 2018, p.450)

Male participants associated masculinity with strength and bravery, living independently, being employed, and being able to provide for a family. The tension between masculinity and disability was highlighted by many studies:

> Not meeting the idealized standards of ''real men'' can cause conflict or tension for men with disabilities; they are expected to be strong and

> independent ‘‘real men’’ and, at the same time, childlike, dependent, and vulnerable. (Björnsdóttir, 2017, p.301)

Possibly due to struggling with this tension, some men with ID expressed their masculinity through sexism and misogyny. “A few of the participants claimed that gay men were not ‘‘real’’ men, they were feminine” (Björnsdóttir et al., 2017, p.301). Men with ID drew on stereotypically masculine activities to describe their self-identities, such as drinking beer, going to strip bars, and fixing cars:

> I like biking by myself in the woods and through mud, it’s interesting to see if I get a little attention from people, it’s funny if they look at me, wondering who I am. (Midjo & Aune, 2018, p.42)

1.2 Sexual Identity. Some participants perceived womanhood and manhood to be associated with romantic experiences such as falling in love and having sexual relations. Both female and male participants conveyed a desire for romantic relationships, however, many had not experienced them. For most female participants, importance of romantic relationships did not correspond with importance of sexuality:

> Eva is a woman in her fifties who has had the same partner for eleven years and who stays at his place in the weekends. She explains that they have never had sexual intercourse and do not intend to in the future either: “No, that is nothing to do. Oh, no”. (Barron, 2002, p.70)

Women held negative views about sex and associated intercourse with risk: “sexual intercourse is… referred to by Anna [as] "not nice and makes you pregnant"” (Barron, 2002, p.70).

> Vera is clear about, as are most of the other participants, that she does not want any children nor does she want to have sexual relations at present. She emphasises … that it is important to say no [to sex]. (Barron, 2002, p.69)

Most female participants struggled to form positive sexual identities and did not expect to experience sexual desire:

> Many of the women seemed to have no concept of themselves as sexual beings. It was difficult for them to even think or talk about sex and their sexuality as if having sexuality simply was not a viable option for them. Some women thought that sex was dirty or disgusting, while others associated it with sickness and disease. (Fitzgerald & Withers, 2013, p.7)

In comparison, male participants were clearly not asexual beings and conveyed sexual urges similar to non-intellectually disabled men. However, both male and female participants were aware of the social censure around the sexuality of people with ID:

> A number of the men had experienced hostility from formal and informal carers and the general public to their having girlfriends. For example, one participant was told that he shouldn't hold hands with his girlfriend when walking down the corridor in college; another described how members of the public had been verbally abusive to him and his girlfriend while they were walking through his home town together. (Wheeler, 2007, p.23)

Expression of sexuality was controlled by parents and support staff:

> The women in this study largely perceived themselves to be passive in relation to sexuality: unable to talk about it or recognise their own desires; expected to accede to the desires of men; regulated, infantilised and controlled by parents, carers and others, they were sometimes unable to recognise that they were 'proper' women at all. (Fitzgerald & Withers, 2013, p.11)

Theme 2: Barriers to Understanding/Developing Gender Identity

This theme describes barriers to understanding/developing gender identity within the ID population, including a lack of personal autonomy due to reliance on support and infantilisation; lack of opportunity and resources for exploring identity; prioritisation of the ID identity above gender identity within society; and stereotypical gender narratives shaping support.

2.1 Barriers to Autonomy. A key theme across studies was that people with ID wanted to be independent; however, reliance on support inevitably impacts personal autonomy. Support providers usually focus on the ID identity as service users' primary identity, therefore people with ID are not encouraged to be "autonomous agents" in their own lives. Men and women with ID tried to fight against this and struggled to assert their independence:

> The welfare and support systems and sometimes staff and family members were the ‘‘enemy’’ they needed to confront and with ‘‘strength’’ and ‘‘bravery’’ they often succeeded in getting improved support and choices. Gunnar a man in his 40s said: … ‘‘I had to fight them [staff] so they would treat us as adults’’. (Bjornsdottir, 2017, p.300)
>
> They *[female participants]* described a constant struggle for making their own choices and although they did not describe themselves as submissive or compliant, which are characteristics of emphasized femininity, they were often expected to be so to staff (Bjornsdottir, 2017, p.302)

The struggle for independence was particularly evident among men. They resisted restrictions imposed by support staff and felt that care was overly controlling:

> Int: When you go with staff to the [mall], are there rules?

> Dan: The rule is like I have to stick with them. Let's say I want to come here to the food court, they would have to come with me and I disagree with that because I'm independent.
>
> Int: What would you rather?
>
> Dan: Just meet them somewhere. (Wilton & Schormans, 2020, p.443)

Group home living environments were highlighted as a particular barrier to autonomy in the lives of people with ID:

> For the four men who lived in group homes, a common theme was the way in which domestic life was controlled and constrained by the authority of staff and the institutional rules of the home. The men exercised little control over daily routines and domestic space. They also had limited control over when they left the home, and how long they were allowed to be away. (Wilton & Schormans, 2020, p.438)

Many participants wanted to live more independently but felt this would not be possible due to finances and/or overprotective carers. Their views were often engulfed by the influences of others:

> **Int** 'So you'd like to live with her, maybe get married and you'd like to have children?' …
>
> **P12** 'It might happen, it might not. It depends'
>
> **Int** 'What sort of things does it depend on?'
>
> **P12** 'My father, my Aunty, my cousins. My cousins are over-protective of me.' (Wheeler, 2007, p.22)

Studies highlighted that people with ID often internalise the stigmatising views of others, impacting their sense of self and expectations for what they can achieve in their lives:

> Society tells disabled young people that they are not to expect the same opportunities and experiences as their non-disabled peers, which is daunting prospect for someone who is young and has their life ahead of them. (Toft et al., 2019, p.164)

Many male and female participants had internalised the negative assumption that they are an incompetent population who are incapable of becoming parents:

> It's no way I'd be able to have a child … Because of the way I am and [...pause...] … Because of my learning difficulties and how the child would respond to the learning difficulties. (Wheeler, 2007, p.23)

Service users also lacked access to other adult roles and consequently struggled to develop positive self-identities. For example, many male participants wanted to be employed and were interested in traditionally masculine roles, however, they struggled to access the labour market. This hindered their ability to express their masculinity and autonomy.

Across included studies it was clear that the infantilisation and overprotection of people with ID restricts gender identity exploration. Participants with ID were "protected" through restricting social activities and limiting access to information, hindering personal autonomy:

> **P12** 'I'd like to go on my own and meet more people'
>
> **Int** 'Right. You were saying that your dad doesn't like you going out on your own' … 'How do you feel about that?'
>
> **P12** 'A bit peed off that I can't go out on my own with other lads'
>
> (Wheeler 2007, p.22)

Studies highlighted the lack of opportunity for people with ID to make decisions in their everyday lives, impeding opportunities for developing gender identity:

> Many participants described how they were not involved in everyday decision making, for example when to do the cooking and cleaning or what should be for dinner, and could seldom choose between staff; that is, who would provide assistance with which task. Also, participants described how they lacked control over their financial affairs and access to adult roles. (Björnsdóttir et al., 2017, p.299)

2.2 Lack of Opportunity to Explore Identity. Reliance on support from ID services reduces opportunities for exploring gender identity. People with ID have less access to regular contexts in which gender identity is developed, such as places of work and leisure activities. Furthermore, support staff have control over access to public spaces, positioning people with ID as dependent on staff:

> Ella, hardly ever goes "to town" despite longing to do so. She requires assistance in order to go, and doesn't wish to bother the staff. … She explains: The staff here much to do so don't think they the time. The girls work so hard. Not want to make trouble. (Barron, 2002, p.75.)

Studies indicated that people with ID lacked opportunities to discuss their self-identity with others. Consequently, many individuals with ID were not able to talk easily about their likes, dislikes and hopes for the future:

> The women presented disjointed and unclear accounts of their identity, perhaps due to lack of opportunity to explore this for themselves. The results suggest that being asked about identity is a rare occurrence for these individuals; this was evident in their surprise and confusion when asked about their personality. (Groves et al., 2018, p.449)

This was highlighted as being a particular problem for men with ID, due to the lack of male staff in ID services. Staff felt that having male staff to spend leisure time with men with ID and talk to them about private matters is important for wellbeing:

> It was beautiful, a beautiful bond with [the male staff member] … a father figure, a male figure … I think it's just a relationship that he has, he obviously knows the difference between male and female. (Wilson et al., 2011, p.347)

It was noted that men with ID particularly enjoyed spending time with staff of a similar age to them:

> He [Client E] does enjoy male companions [staff]. … He just enjoys the company. … Normally when they [male staff] are younger too, not so much the older ones … a similar age, early 20s I think it is just that little bit more in common … when you've got someone [a male staff member] around their age, I think you find it, it's like wow!, you know? (Wilson et al., 2011, p. 347)

Female staff noted that without male staff around there is less opportunity for men with ID to do masculine recreational activities. For example, it was observed that one male service user enjoyed playing football with male staff but was not interested in playing with female staff. Furthermore, female staff were more fearful of male sexual expression and more reluctant to talk to men with ID about sexual issues:

> I am just more careful around sexual areas when I am working with men, I don't like to, sort of, put any ideas in their heads, or to encourage them in anyway by talking about it … I'd hate to think that they would get some sort of idea about anything [sexual]. (Wilson et al., 2011, p.345)

Individuals with ID lacked resources for identity construction due to restricted access to adult TV programmes and the media, and lack of involvement in activities such as clothes shopping. Consequently, they struggled to make sense of who they are with limited guidance and role models. Unsurprisingly, participants with ID lacked knowledge of diverse sexual orientations and gender identities:

> The men who participated in this research all identified as heterosexual and had in general limited knowledge of sexual orientations. Few were aware that disabled men could be gay and one young man said: ‘‘No we cannot be gay. Maybe possible in other countries but in Iceland gay is only for famous people like Paul Oscar [Icelandic queer pop-star]’’. Gay or queer masculinity was, therefore, only available to public figures such as pop stars. (Björnsdóttir et al., 2017, p.301)
>
> none of the women in the study appeared to have considered adopting anything other than a heterosexual identity (Fitzgerald & Withers, 2013, p.8)

They had internalised a societal perception of themselves as intellectually disabled rather than “proper” men and women. However, they also lacked knowledge about the ID diagnosis, leading to disjointed self-concepts:

> Down’s Syndrome it’s like, it’s disability but it’s confusing. I don’t know what it is. (Groves et al., 2018, p.449)

2.3 Competing Identities. Studies highlighted that the ID identity can be a barrier to the development of gender identity. There is a disparity between how society views people with ID and how they see themselves:

> The young disabled LGBTQ people we spoke to work hard to construct their identities against societal perceptions which are perpetuated through misconceptions about disability, sexuality, and gender. (Toft et al., 2019, p.169)

Participants with ID perceived gender to be an important part of their self-identity and saw themselves as similar to non-intellectually disabled men and women:

> 'I am a normal man' (Elliot); 'I am a beautiful lady' (Lily); 'I am a grown man' (George) (Brown 2010, p.221)

However, they struggled to be recognised as gendered individuals, were disbelieved if they questioned their gender identity, and had internalised a view that they should not pursue gendered and sexual expression:

> The struggle that young disabled people experience in establishing and 'proving' themselves as a competent and sexual individual who identifies as LGBTQ, could have implications for their identity development and wellbeing. (Toft et al., 2019, p.167)

Participants with ID did not identify closely with the ID identity. It was clear that they wanted to talk about gender identity but not the ID identity:

> Boys were eager to talk about how they conducted their lives as boys, in a very tangible and celebratory account of boyhood from their perspective" … "Boys were careful not to frame their accounts in the context of difference or allow their ID to dominate their accounts of their masculinity. (Charnock & Standen, 2013, p.339)

However, other people in greater positions of power were focused on the ID identity:

> There was a common feeling among the young people that even if society accepts them as sexual beings, they must be straight: "People don't expect you to have that interest, and even if they did would presume that you're straight because it's not generally advertised that disabled people can be gay, they can be transgender, people are just blind to it". (Bridget) (Toft et al., 2019, p.164)

The desire to be "normal" and to "fit in" was a strong theme among participants with ID. They struggled with feelings of difference and were aware that being categorised as intellectually disabled involves stigmatisation. Many tried to distance themselves from the ID identity by positioning themselves as capable and independent:

> I help the staff, like to make the games and like to help people who can't do things. I, l like to be helping with the staff. I help the staff to help other people who can't do it. (Groves et al., 2018, p.450)

People with ID also used stereotypical and valued gender roles such as fiancée and bride to resist the ID identity. "Where discourses of intellectual disability originate from ideas of incapacity and lack, gender presented opportunities for competence and the experience of being loved and valued" (O'Shea 2020, p.669). Some participants with ID hid their norm-breaking gender/sexual identities for fear of rejection or discrimination. They felt that they lacked control over the ID identity as they were unable to choose not to reveal it.

2.4 Gender Normativity. Studies highlighted that heteronormative assumptions among those providing support produce stereotypes among those being supported. Groves et al. (2018) noted that the women in their study "appeared to have quite restricted views of the possibilities and opportunities that are available to them,

choosing to define a woman by stereotyped interests and hobbies" (p.450). Support services reinforce gender stereotypes through the gendered activities offered to service users:

> Education and support systems have normalized gender for people with intellectual disabilities; they are supposed to have access to ‘‘normal’’ lives and, therefore, educational opportunities and services are organized around the idea of ‘‘normal’’ femininity and masculinity; that is, hegemonic heterosexual femininity and masculinity. (Björnsdóttir 2017, p.307)

Consequently, service users are treated as though they identify with the gender they were assigned at birth. This can be particularly problematic for people with severe and profound ID:

> One example was a young woman who needed assistance with all activities in her daily life and used alternative modes of communication; she did not like being touched, especially not her hands, but support staff frequently put polish on her nails. (Björnsdóttir 2017, p.307)

Both staff and service user participants acknowledged that society is blind to the possibility of people with ID having norm-breaking gender and sexual identities:

> It was common for participants [healthcare professionals] not to have considered the topics of sexuality and LGBTQ issues at all in relation to their patients, and it was usually assumed that the patient was identifying with their biological sex and was heterosexual. (Sommarö 2020, p.7)

Theme 3: Recommendations for Practice

This theme describes facilitators to the understanding/development of gender identity and recommendations for improving practice, including promoting service users' autonomy and increasing opportunities for identity exploration.

3.1 Opportunities to Explore Identity. Service providers need a proactive approach to providing opportunities for people with ID to explore their identities. People should be supported to express who they are through clothing and other means of their choice. It was clear that participants with ID valued opportunities to talk about their self-identities and were eager to tell their stories. However, opportunities for this were lacking, and some relied on their imaginations to explore their identity. One study highlighted that videogames allowed boys with ID the freedom to practice dominant forms of masculinity, free from restrictions on their independence. They enjoyed embodying hyper-masculine characters, enabling them to develop their sense of autonomy and masculinity:

> The dominant factor is the boys' desire for autonomy and independence through an unrestricted medium for testing how to be boys without the complication of disability. (Charnock & Standen, 2013, p.341)

Some studies found that LGBTQ support groups helped people with ID to develop more positive gender and sexual identities, through meeting people with diverse identities in a safe space without fear of judgement:

> 'When I'm at [support group] I can experiment with different clothing without being judged. I have done so before. Everyone is completely fine with it because we have a lot of Trans members and everyone is completely accepting of them. So me wearing something a bit different is nothing to them, oh

another person just experimenting with gender and stuff' (Aaron). (Toft et al., 2019, p.168)

Role models were highlighted as being important for creating a valued sense of masculinity/femininity. The value of interaction with male staff of a similar age for male service users was noted by support staff.

3.2 Promoting Autonomy. Studies emphasised the need to promote service users' autonomy, to support the development of gender identity (Bjornsdottir et al., 2017; Björnsdóttir & Stefánsdóttir, 2020; Brown et al., 2010; Charnock, 2013; Fitzgerald & Withers, 2013; Groves et al., 2018; Midjo & Aune, 2018; Wheeler, 2007; Wilton & Schormans, 2020). The ID population should be empowered to have more control over their lives, including a more active role in everyday decision-making and creating their own care plans. People with ID need to be given real choices, including the freedom to accept or decline support from different support workers. Accessible information to support service users with decision-making is imperative:

> Possessing personal autonomy and agency is fundamental for the development of gender and sexual identities. Issues such as access to information, ability to choose and being able to communicate are important for personal autonomy, as is the ability to reflection oneself and one's choice. Although these are important concerns, it does not mean that those who do not possess these abilities or those who need help in applying them should be denied personal autonomy. (Björnsdóttir et al., 2017, p.308)

Staff should address any misinformation among service users, including confusion about what disability means and damaging attitudes such as sexism and homophobia.

Service users also need increased support to access the community, to access valued social roles such as employment, which can buffer against negative social comparisons in the lives of people with ID. It was notable that male participants with ID who lived with carers and were in paid employment did not report lacking autonomy in their lives; however, those without jobs did (Wilton & Schormans, 2020).

People with ID need to be asked about their support preferences around gender issues and given a voice. Service providers need to be aware of internalised oppression and work in a way that encourages service users to speak for themselves. The number of advocacy services should be increased, and support services should have gender-specific and LGBTQ training. Developing coherent models of gender identity in the ID population, in collaboration with service users, may help to shape support.

Synthesis of Quantitative Research

The systematic review found six quantitative or mixed-methods studies. A narrative synthesis of these studies is provided below.

Two studies analysed the attainment of gender identity among children with ID, defined as the ability to identify themselves as male or female. Abelson and Paluszny (1978) used the Michigan Gender Identity Test to assess whether children could accurately categorise photographs of males and females, and of themselves. They found that IQ was an important factor in the attainment of gender identity,

however, age was not. In comparison, age and IQ were both significantly correlated with attainment of gender identity among neuro-typical children. The second study (Kifune, 1990) used the Draw-A-Person procedure to analyse whether children with ID drew a self-sex figure first. They found that age and severity of ID did not determine attainment of gender identity. However, children with ID drew a self-sex figure first less frequently than neuro-typical children. Neither study found gender differences in the attainment of gender identity among children with ID.

Two studies used descriptive designs to examine the different gender identities of people with ID. Bedard et al. (2010) found that 12.9% of their sample had gender identity dysphoria (GID), indicating that GID could be more common among people with ID. However, the sample cannot be considered representative because participants were accessing psychiatric services. The individuals with GID did not have a higher prevalence of other diagnoses (such as Autism or schizophrenia). Parkes et al. (2009) reported a range of gender identities comparable to the general population in their sample. A high level of reported childhood abuse and mental health problems were found among participants who cross-dressed or had gender dysphoria. Reasons for cross-dressing were wide-ranging, including sexual motivation, discomfort about being gay, and escaping trauma.

Two studies employed cross-sectional designs. Burns and Davies (2011) examined the relationship between stereotypical gender role beliefs and attitudes towards homosexuality among women with ID. They found that the women held very traditional views of gender roles, and these views were strongly associated with more negative attitudes towards homosexuality. Umb-Carlsson and Sonnander (2006) explored gender differences in the living conditions of people with ID and compared

the results with the general population. Overall, there were significantly fewer gender differences in living conditions (for example, finances, family relations, and personal safety) within the ID population compared to the general population. However, in both the ID population and the general population, job roles were stereotypically gendered.

Discussion

The mixed-methods review aimed to explore how people with ID understand their gender identity, and how this is or is not facilitated by the staff that support them. Studies revealed that men and women with ID frequently struggle to understand their gender identity. Service users did not identify closely with the ID identity, resisting it by positioning themselves in socially valued (and often stereotypically gendered) roles. However, the ID identity overshadowed the status of people with ID as "real" men and women, and there was a striking disparity between how society perceives the ID population and how they see themselves, in line with previous research (Aull Davies & Jenkins, 1997; Wilkinson, 2013). The tension between masculinity and disability was also apparent in the review, and is a much cited observation in the wider literature (Shuttleworth et al., 2012).

Review findings highlighted barriers and facilitators to understanding/developing gender identity within the ID population, which translated into implications for improving practice (see Clinical implications section, p.58-60). Reliance on support impedes personal autonomy and identity development, because support providers are focused on the ID identity above other identities, leading to infantilisation. Studies emphasised that people with ID need more control over their own lives, including accessible information to support with everyday decision-making.

Participants with ID in the included studies often relied on stereotypical gender narratives when articulating their gender identity. The social cognitive theory of gender identity development states that gender stereotypes are learned from observing the differential behaviour of male and female role models (Bussey & Bandura, 1984, 1992, 1999). It has been observed that traditional structural arrangements of gendered interactions often prevail in ID services. The division of staff roles often reproduces traditional patterns of power, in which women provide the care and men occupy the higher status managerial roles and look after discipline (Clements et al., 1995). Furthermore, the review findings highlighted that ID services reinforce gender stereotypes through the activities offered. Organisations stratified by gender restrict exposure to diverse gender roles and styles of conduct (Bussey & Bandura, 1999), possibly explaining the dominance of stereotypes in the self-concepts of participants with ID.

It has been noted that the primary goal for ID services is promoting independence and self-sufficiency, which is traditionally a masculine value (Brown & Smith, 1989; Clements et al., 1995). If feminine values prevailed, interdependence and relationships would potentially be more dominant (Clements et al., 1995). The review findings showed that female participants with ID referred to biological aspects such as menstruation and pregnancy, and feminine appearance and clothing, when discussing womanhood. Other culturally valued feminine traits, such as emotional intelligence and empathy, were not attended to. It is possible that this is because these traits are not reinforced to the extent that independence and daily living skills are within ID services. Research shows that people are not motivated to perform gendered behaviour unless they believe it will produce valued outcomes (Bussey & Bandura, 1999).

Participants with ID perceived gender identity to be an integral part of who they are and yet struggled to be recognised as gendered individuals. Perceiving people with ID as gender-less in a gendered world is extremely damaging, infantilising service users and preventing them from achieving adult status (Clements et al., 1995; Thompson, 2014). The review findings support this, showing that people with ID lack access to adult roles such as employment and parenthood, preventing the development of a valued identity. This is concerning, because research has shown that 'ordinary' and valuable social roles make people with ID feel satisfied with their lives (Haigh et al., 2013; Richards, 2018). Government programmes and policies intended to promote equality and the wider social inclusion of people with ID appear to have gone only so far in improving their daily lives (Building the Right Support, 2015; Department of Health, 2009; Transforming Care 2015).

Service users often linked romantic experiences with gender identity and conveyed a desire for romantic relationships. However, many had not experienced intimate relationships, and both men and women were aware of the social censure around the sexuality of people with ID. It has been suggested that infantilisation and restricted opportunities for sexual exploration and relationships may impact gender identity among people with ID. For example, cross-dressing and transsexualism may be a method for exploring sexuality (Bowler & Collacott, 1993; Wood & Halder, 2014).

Review findings demonstrate that the ID identity can be a barrier to the exploration of gender identity, because people with ID have a strong desire to be considered "normal". This is echoed by a study on sexual identity development that found that people with ID seek to be "as normal as possible" to compensate for the ID identity (Wilkinson et al., 2015). It has been noted that people with ID who identify as

LGBT often experience ‘layered stigma’ because of their dual minority statuses (McCann et al., 2016). For example, (Löfgren-Mårtenson, 2009) found that support staff perceive people with ID who identify as homosexual as possessing an additional unnecessary ‘deviation’ or disability. Furthermore, Parkes et al. (2009) found that some people with ID cross-dressed because they were homosexual and felt that their sexuality would be more acceptable or “normal” if they were the opposite sex. Rules that define normality and have been socially constructed by dominant groups in society likely hinder the exploration of diverse identities among both the ID and general populations.

The review highlighted that reliance on ID services means that people with ID have less access to role models and guidance for identity exploration, leading to a lack of knowledge about diverse identities and disjointed self-concepts. Erik Erikson’s (1968) theory of psychosocial development suggests that feedback from peers helps one to develop a sense of self through mirroring and modelling practices (Dole, 2001; Forber-Pratt et al., 2017). Unfortunately, people with ID lack access to different contexts for exploring identity, resulting in smaller social circles (Björnsdóttir & Stefánsdóttir, 2020). They therefore rely heavily on support staff as role models. Research has shown that children prefer to pay greater attention to same-gender than other-gender models (Bussey & Bandura, 1984, 1992). Correspondingly, support staff have observed that men with ID flourish in the company of male staff of a similar age (Wilson et al., 2011). The shortage of male support staff in ID services may therefore pose a problem for male service users (Hatton et al., 1999; McConkey et al., 2007). Furthermore, few support staff who identify as LGBT have disclosed their “non-normative” identities to service users, denying them access to potentially positive role models (Abbott & Howarth, 2007; Charnock, 2013; Noonan & Gomez, 2011).

Methodological Considerations

The strengths, limitations, and methodological variation in the included research was considered when synthesising the data. The lower overall quality of the quantitative compared to qualitative research in the review was notable, demonstrating that high quality quantitative studies in the ID population are lacking and/or that the review research questions do not lend themselves to quantitative research. Two older quasi-experimental studies conducted in 1978 and 1990 and one study using a case series design reported insufficient detail to describe the research processes, leading to numerous "unclear" quality ratings. The two cross-sectional analytical studies conducted more recently experienced some obstacles to high quality ratings due to the lack of robust research in the ID population, for example, study measures had not been validated for the ID population.

Many included studies used purposive sampling; however, over half relied on convenience sampling, which limits the validity of findings (Ritchie et al., 2013). The use of focus groups in three of the qualitative studies (used solely in one study, and alongside individual interviews in the others) may have further undermined validity, as certain voices can be marginalised (Barker et al., 2002). Additionally, studies including support staff participants involved overrepresentation of the voices of female staff, likely representing the shortage of male staff in ID services as opposed to being an issue with study recruitment. The voices of people with more severe/profound ID were also underrepresented, which is problematic considering that people with profound ID are often not provided with services that adequately meet their needs (Mansell, 2010).

Most qualitative studies used thematic analysis or inductive analytic approaches involving a lower level of interpretation compared to grounded theory and IPA (Vaismoradi et al., 2013). It could be argued that data from the three IPA or grounded theory studies may be more likely to be misrepresented in a thematic synthesis, as researchers stay less close to the original data (Smith & Osborn, 2015). Many qualitative papers failed to specify the qualitative design and theoretical framework underpinning their research, making it difficult to evaluate the rigour of the analysis (Murphy et al., 1998). Whilst it is known that high quality qualitative research should present analyses coherently and transparently (Elliott et al., 1999; Yardley, 2000), variation and flexibility in qualitative analytic approaches can make it difficult to ascertain the inductive steps (Walsh & Downe, 2006). Furthermore, some included studies used additional participatory activities (such as accompanying participants on research journeys throughout a city) alongside more traditional data collection methods such as interviews. Although participatory activities are beneficial for improving accessibility for research participants with ID, they may have made it difficult to be exact when describing the steps involved in the research process. Despite the emphasis on reflexivity in quality guidelines for qualitative research (Elliott et al., 1999; Yardley, 2000), many included papers did not address this in sufficient detail (and several not at all). However, Walsh and Downe (2006) suggest that this is often due to restrictive word counts for publishing papers, rather than being omitted from the research process.

Strengths and Limitations

A key strength of this review is the mixed methods design, allowing for a more comprehensive synthesis of evidence and a greater breadth and depth of

understanding than can be offered by single method reviews (Dixon-Woods et al., 2005; Sandelowski et al., 2012). Mixed methods reviews are more methodologically inclusive in order to maximise the ability of the findings to inform policy and practice (Harden, 2010). However, a limitation is the degree of complexity involved in completing a mixed methods review, and the lack of universally adopted method or guidance for conducting them (Hong et al., 2017; Petticrew et al., 2013). It is possible that the relatively large number of included studies and volume of data could hinder the analytic depth of the review (Bondas & Hall, 2007). Conversely, the small number of quantitative studies included in the review, with their wide range of methodological designs, sampling approaches, and data collectinon methods, made it challenging to meaningfully synthesise quantitative research findings.

A second key strength of the review is that handsearching of reference lists yielded no new papers, indicating a robust search strategy. However, exclusion of unpublished and non-peer-reviewed papers may have led to loss of some relevant research and publication bias (Petticrew et al., 2008). The breadth of the studies synthesised is a strength of the review. However, publication dates of included studies spanned from 1978 to 2020, which could be a limitation due to probable change in attitudes and/or service delivery during that time.

Harris et al. (2014) recommend a minimum of two reviewers for determining study eligibility for inclusion in a review. This recommendation was not adhered to, limiting the rigour of the review. To mitigate the impact of this, all full text articles where there was any uncertainty around study eligibility were reviewed by and discussed with a second independent reviewer, and a collaborative decision was reached. Study authors were not consulted regarding the thematic synthesis; therefore,

it is possible that the analytical themes produced may not fit with the researchers' conceptualisations of the original study data. It is notable that only three included studies involved support staff participants, limiting the conclusions that can be drawn about the perspectives and experiences of staff regarding the research questions.

Clinical Implications

Professionals who support people with ID need to shift from a paternalistic approach to a collaborative and proactive approach to gender identity development (Groves et al., 2018). People with ID require specific education about gender identity development that covers the complexity of gender identities and challenges stereotypical gender roles (Wheeler, 2007; Wilkinson, 2013). A proactive approach is needed to enabling opportunities for identity development, particularly opportunities to socialise with and receive feedback from peers, in order that their identities can be explored and consolidated. Increased social groups, education groups, and support groups for people with ID should increase opportunities for talking about and exploring gender identity.

Policy should reflect the key role that support services play in supporting people with ID to promote the identities they wish to be recognised by (Brown et al., 2010; Charnock & Standen, 2013). It is important for service managers and policy makers to reflect on and strive to overcome the gender-blindness within services that is so damaging to the self-identities of people with ID. Gender needs to be recognised and attended to in service policies, and gender-specific training for staff is needed (McCann et al., 2016; Wilson et al., 2011).

Reflective practice groups for staff could help to reduce the focus on the ID identity to the exclusion of other identities. It is anticipated that reduced focus on the

ID identity should translate into reduced infantilisation and overprotection, increased personal autonomy, and increased access to adult, gendered, and socially valued roles for people with ID. This should help to close the noted policy-practice gap in terms of inclusion in society and standards of support (Charnock, 2013; Dinwoodie et al., 2020), and help people with ID to lead more 'ordinary' lives (Clements et al., 1995).

Review findings highlighted the importance of promoting service user autonomy, particularly for men with ID, which has also been emphasised in other research with men with disabilities (Joseph & Lindegger, 2007; King et al., 2020). Services should be aware of internalised oppression among services users and ensure that people with ID feel able to speak for themselves (Björnsdóttir & Stefánsdóttir, 2020). Increased advocacy services would be helpful in this regard (Fitzgerald & Withers, 2013; Midjo & Aune, 2018), increasing the control that people with ID have over their lives and furthering understanding of their support preferences around gender issues.

It has been acknowledged that the gender normativity bias within services is particularly problematic for people with severe/profound ID, who may be automatically treated as though they identify with their biological gender and are less able to express choices (Björnsdóttir & Stefánsdóttir, 2020; Thompson, 2014). Support providers should be vigilant toward heteronormativity and prejudice that may exist within organisations, blinding staff to the fact that people with ID can have "norm-breaking" gender identities (Gomez, 2012; McCann et al., 2016). Facilitated reflective practice groups may help support staff to reflect on their assumptions, ensuring that these are not being translated into stereotypes among the people they support. The stigma around the ID identity also needs addressing, so that people with ID feel able to explore non-normative identities without fear of 'layered stigma'

(Fitzgerald & Withers, 2013; Groves et al., 2018). A proactive approach is needed to seek out role models with diverse experiences and identities for service users. Furthermore, the shortage of male support staff needs addressing in order to increase access to male role models for men with ID (McConkey et al., 2007).

Future Research

Considering the lack of robust theory around identity development among people with ID, future research could seek to develop coherent models of gender identity in this population, to shape future support in this area. This review confirms that few studies have been conducted which ask people with ID about their gender identity. This is disappointing, considering the good practice recommendation to ask service users directly about their views and experiences to ensure quality of services (Department of Health, 2008). Improved understanding of the support needs of people with ID is necessary to develop policy around gender issues and translate it into sustainable and meaningful practice (Charnock, 2013). There is an increasing focus on the different types of evidence that policy makers require to make decisions, such as priority, feasibility, and service user preferences (Alonso-Coello et al., 2016; Aromataris & Munn, 2020; Zhang et al., 2019). Consequently, data that respond to these different types of questions are useful for guideline development (Aromataris & Munn, 2020), indicating that both quantitative and qualitative research is needed in this area.

Research allowing the voices of the ID population, including those with severe/profound ID, to be heard is a crucial first step to ensure changes that are important to them occur. Inclusive and flexible research methods and service user forums could facilitate this (Gilbert, 2004; Jahoda et al., 2010). The review highlighted a clear gap in the literature in relation to studies on the experiences and

views of support workers. There was a dearth of research involving male staff. Future research could explore staff perspectives on facilitators and barriers to supporting people with ID to develop their gender identity, with a specific effort to recruit male staff participants.

Conclusion

This mixed-methods systematic review revealed the struggle that people with ID experience in understanding their gender identity, which is overshadowed by the ID identity. Gender normativity bias within ID services, and a desire to be "normal" among people with ID, leads to stereotypical views and hinders exploration of diverse identities. The review highlighted a range of barriers and facilitators to supporting people with ID to develop their gender identity, which can be used to inform policy and clinical practice and improve service provision. The findings emphasise the need for gender-blindness in services and policies to be addressed. A proactive approach is needed to promoting service users' personal autonomy and providing opportunities for them to develop gender identity.

Paper 2

Embracing Gender Identity in People with Intellectual Disabilities

Empirical Study

Abstract

Gender identity is a highly important determinant of health, but little is known about the gender identity of people with intellectual disabilities (ID). The feminisation of ID services and disproportionate number of female compared to male support workers may be problematic for the development of masculinity for males with ID. Research has shown that the gender of support staff affects the type of care provided, either promoting or hindering quality of life. No study has explored the self-reported experiences of both staff and male service users around issues related to gender and masculinity and support in this area. The present qualitative study therefore aimed to further understanding of this under-researched area. Separate semi-structured interviews were conducted with 5 men with ID and their support workers. Interview data were analysed using Interpretative Phenomenological Analysis. The analysis produced three main themes: (1) Understanding of gender and identity, (2) Barriers to support with developing gender identity, (3) Facilitating factors to developing gender identity. Being a man was an important and positive aspect of life for all men with ID, however, they struggled to be recognised as gendered individuals because the ID identity can overshadow gender identity. The development of gender identity can be hindered by stigma, internalised oppression, and ID service constraints and priorities. If the Government's objective to support people with ID to develop valued social identities through inclusion in society is to be met, these barriers must be addressed. The facilitators and barriers to gender identity development highlighted by the study enable practical suggestions for improving support in this area, with the aim to close the current gap between policy and practice.

Keywords: intellectual disabilities, learning disabilities, qualitative interviews, gender identity

Introduction

It is widely accepted that there are three aspects to gender: biological, social role, and identity (Thompson, 2014). It is now known that gender identity is influential for quality of life, and a highly important but under-acknowledged determinant of health (Evans et al., 2011). However, little is known about the gender identity of people with ID (Bedard et al., 2010), and research has shown that people with ID often do not have a clear sense of their self-identity (Fitzgerald & Withers, 2013; Wilkinson, 2013). Evidence from both research and practice has shown that not only do people with ID have poorer health, but these health differences are often related to social factors (such as social exclusion and barriers to accessing services) and are consequently avoidable and unjust (Commission on Social Determinants of Health, 2008; Graham, 2005; Krahn et al., 2006; Mencap, 2012; Merrick & Merrick, 2007; Michael & Richardson, 2008; Ouellette-Kuntz, 2005). Researchers have emphasised that to overcome the health inequalities, action must be taken to address the social inequalities that marginalise the ID population (Allerton et al., 2011).

Gender Blindness in Support Services

The support systems of people with ID are fundamental to their identity development (Dole, 2001). However, there is a noted dearth of guidance on supporting people with ID to develop their gender identity (McCann et al., 2016; Wilson et al., 2018). Consequently, studies have shown that there is a lack of appreciation among staff of the wide range of gender experiences that exist among service users (Sommarö et al., 2020), and support services often adopt a gender-blind approach (Löfgren-Mårtenson, 2009; Umb-Carlsson & Sonnander, 2006). Practice guidelines tend to be written in gender-neutral language, therefore offering limited

gendered guidance (Wilson et al., 2009). Treating a person as genderless in a gendered world is extremely damaging to their sense of self, denying them core experiences and access to valued social roles (Clements et al., 1995). Gender-blindness in ID services is therefore a barrier to social inclusion, which has been emphasised as a priority in the Government's Valuing People Now strategy to improve the lives of people with ID (Department of Health, 2009).

Masculinity in the general population

Dominant theories in the psychology of men and masculinities posit that gender roles are acquired through a social conditioning process that starts at an early age and is informed by gender ideologies (Gerdes, Alto, Jadaszewski, D'Auria, & Levant, 2018; Levant, 1995; Pleck, 1995). Masculinity ideologies have been defined as an internalisation of cultural attitudes toward men's roles and masculinity (Gerdes et al., 2018; Levant & Richmond, 2008). Correspondingly, general consensus is that masculinity is a social construction, and within any given society or timepoint in history an idealised version of masculinity can become dominant or hegemonic (Connell, 1987; Evans, Frank, Oliffe, & Gregory, 2011). Contemporary hegemonic masculinity in Western culture, termed "traditional masculinity", is associated with physical strength, dominance, power and control, assertiveness, emotional restraint, independence and self-reliance, heterosexuality, hypersexuality, homophobia, and avoidance of femininity (Brannon & David, 1976; Connell & Messerschmidt, 2005; Gerdes et al., 2018; Levant, 1995; Mahalik, Good, & Englar-Carlson, 2003; Thompson Jr & Pleck, 1995). It has been observed that many men do not measure up to this hegemonic version of masculinity against which all men are judged and

consequently experience marginalisation and subordination (Connell, 1993; Evans et al., 2011).

Cultural shifts over time have weakened the endorsement of Westernised hegemonic masculinity, and other theories have emerged to account for changes in the dynamics of male peer group cultures (Anderson & McCormack, 2018). For example, research has found that many young straight men reject homophobia, embrace bisexuality and activities once defined as feminine, and are emotionally open with friends (McCormack & Anderson, 2014). Inclusive Masculinity Theory (IMT: Anderson, 2010) stems from such research and argues that social changes are gradually allowing more diverse forms of masculinity to become more evenly respected (Anderson & McGuire, 2010). However, there is a long way to go (Anderson & McCormack, 2018).

It is now understood that masculinity interacts with other social determinants of health to create health disadvantages among men (Evans et al., 2011). Health-promoting behaviours are aligned with traditional femininity, whereas masculinity is associated with risk-taking health behaviours. Consequently, it has been proposed that men's endorsement of masculine ideals contributes to the health disparity between men and women (Courtenay, 2000; Ratner, Bottorff, Johnson, & Hayduk, 1994; Saltonstall, 1993; World Health Organization, 2000). Furthermore, subgroups of men categorised by marginalised masculinities (for example, based on sexual orientation or ethnicity) experience poorer health outcomes compared to other more dominant groups of men (Evans et al., 2011; Schofield, Connell, Walker, Wood, & Butland, 2000).

The Conflict of Disability and Masculinity

The conflict between masculinity and disability is well-documented in the literature; with disability perceived as synonymous with being childlike and dependent on others, and masculinity with autonomy and independence (Shuttleworth et al., 2012; Wilton & Schormans, 2020). Despite this dilemma, research exploring the relationship between disability and masculinity/gender identity is lacking (King et al., 2020; Loeser et al., 2017; Thomas, 2006). The limited research has typically focused on physical impairment (Gerschick, 2000; Nakkeeran & Nakkeeran, 2018), or has focused on 'disability' as a homogeneous category without acknowledging different types of impairment (King et al., 2020; Shuttleworth et al., 2012). Studies within the ID literature have largely focused on gendered issues faced by women. An analysis of gender-specific topics in the ID literature revealed that less attention is paid to male compared to female health, and gendered issues for men are reduced to issues of behavioural risk at the expense of health promotion (Wilson et al., 2010). It has been suggested that men with ID can be unnecessarily pathologized as violent, abusers, or sexual deviants; leading to less focus on (and consequently poorer) health outcomes (Wilson et al., 2009).

Existing Research

Researchers have urged that theories of masculinity may offer a useful framework for research and therapeutic interventions with men and boys with ID, and studies using theories of masculinity to understand how men negotiate the intersection of masculinity and ID are needed (Shuttleworth et al., 2012; Wilson et al., 2012). Four studies (with a total combined sample of 38 men with ID) have investigated the relationship between ID and gender/masculinity from the perspective of male

participants with ID. Two of these studies involved mixed samples of both men and women (Bjornsdottir et al., 2017; Mutua & Swadener, 2015), and two focused exclusively on the experiences of men with ID (Charnock & Standen, 2013; Wilton & Schormans, 2020). In summary, the evidence indicated that men with ID struggle to assert their autonomy and lack access to adult roles, impeding the development of a valued adult identity. Furthermore, the ID identity and reliance on support can hinder the development of gender identity. Researchers have asserted that there is a patent need for further research to examine the relationship between ID and masculinity (King et al., 2020).

The Influence of Support Networks on Identity Development

Social cognitive theory of gender identity development in the general population states that a person's immediate environment, caregivers, peers, and education are inextricably involved in their gender identity development (Bussey & Bandura, 1999). Not surprisingly, support staff are recognised as having a huge impact on the lives and identities of people with ID (Wilson et al., 2011). Research has shown that heteronormative bias among staff and masked power in care work may restrict identity development among service users (Midjo & Aune, 2018; Sommarö et al., 2020). It has been argued that there has been insufficient effort to enhance relationships between support staff and ID service users (Clegg & Lansdall-Welfare, 2010), and research exploring the gendered relationship between support staff and service users is lacking (Hatton et al., 2004; Wilson et al., 2009). One study explored staff perspectives and showed that staff can and do have a gendered influence, both positive and negative, over men with ID; and an environment where maleness is positively valued may have positive outcomes for male health (Wilson et al., 2009;

Wilson et al., 2011). Study participants with ID were unable to participate in interviews due to severe cognitive impairment, therefore their experience was inferred via the interviews with their support workers.

Feminisation of ID Services

The feminisation of ID services and disproportionate number of female compared to male support workers may be problematic for the development of masculinity for men with ID (Treacy & Guerin, 2019). Between 80-95% of paid caregivers are female across all social care sectors in the UK, with similar proportions in the USA (McConkey et al., 2007). Small-scale studies specifically in the ID service sector suggest a similar gender-ratio imbalance (McConkey et al., 2007). This is problematic, considering that a larger proportion of the client group of ID services are male than female (McConkey et al., 2006). An obvious concern is whether a predominantly female workforce can adequately support men with ID to explore their identities and develop their masculinity, within an environment that is characteristically feminine (McConkey et al., 2007; Parkes et al., 2009; Wilson et al., 2009). Research has shown that the gender of support staff affects the type of care provided, either promoting or hindering quality of life (Wilson et al., 2011). The feminisation of ID services may cause men with ID to withdraw from traditional models of healthcare delivery, negatively impacting male health outcomes (McConkey et al., 2007; Treacy & Guerin, 2019; Wilson et al., 2009; Wilson et al., 2011).

The Present Study

To our knowledge, no study has explored the self-reported experiences of both staff and male service users around issues related to gender and masculinity and

support in this area. The present qualitative study therefore aimed to further understanding of this under-researched area. The following research questions were explored:

- What are men with ID and their (male/female) support workers' perspectives of male gender/masculinity in men with ID?
- What factors either support or hinder the development and expression of gender identity among the men in our sample, from the perspective of men with ID and their support workers?

The definition of gender identity adopted in this study was the deeply felt and personal sense of oneself as being a woman or man (ONS, 2019; Reed et al., 2009). This sense is separate from biological sex and social roles (Thompson, 2014). The three commonly described aspects of gender (biological, social role and identity) all impact on mental health and wellbeing and were explored in the study. It was anticipated that the knowledge generated by the study would provide initial ideas and insight into how services can improve support around the development of gender identity for men with ID.

Method

Design

A qualitative dyad study design was used, comprising of 10 individual semi-structured interviews. Separate interviews were conducted with each member of the dyads, allowing comparison between service user and support worker perspectives (Eisikovits & Koren, 2010). A qualitative approach was deemed appropriate because this is a new area of investigation and our aim was to gain a rich understanding of how participants made sense of their experiences (Harper & Thompson, 2011). Data

were analysed using Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009).

Participants

Five men with ID (mean age 26 years and 8 months) and their support workers (totalling 10 participants) were recruited from two supported living or community support work services, in two counties in the South East of England. Tables 5 and 6 summarise participant demographic information. Men were eligible to participate if they were known to ID services, aged between 18 and 35 years old, had capacity to give verbal consent to participate, and were able to engage verbally with the interview. Participants were therefore likely to have mild-moderate ID (supporting the homogeneity of our sample and expanding on previous literature). Considering the larger body of research on gender identity in the Autism population, participants with ID were excluded if they had a formal diagnosis of Autism, in order to focus primarily on the ID population. Support workers were eligible to participate if they were paid to support the person with ID, had been working closely with the service user for at least two months, and provided support sessions at least weekly.

Purposive sampling was employed due to the aim of IPA to understand the insights of a reasonably homogenous sample (Harper & Thompson, 2011; Smith et al., 2009). We aimed to recruit at least 2 male support workers. We recruited a mixture of young men who lived in supported living and family homes. Following the tenth interview, the research team agreed that a larger sample size would dilute the richness of the data and hinder the reflexive analysis process (Smith et al., 2009) and recruitment was terminated.

Suitable recruitment sites were identified by the field supervisor and other professionals working in ID teams. The lead researcher contacted the managers of five ID services and asked them to assist in identifying and recruiting young men with ID. Three of the five services did not identify any suitable participants. Service managers provided study information sheets (an accessible version for men with ID) to potential participants and asked if they would like to meet with the researcher. Service managers then put the lead researcher in contact with support workers via email. Service users received £10 payment for participation in the study.

Table 5: *Service User Demographics*

Pseudonym	Gender	Age	Ethnicity	Religion	Living situation	Gender mix of home environment
Johnny	Male	24	White British	None	At home with family	Living with Mum and Stepdad
Thomas	Male	30	White British	Christian	At home with family	Living with Grandmother
Noah	Male	31	White British	None	Supported living	Living with one male
Matthew	Male	20	White British	Christian	Supported living (24-hour support)	Living with two females and one male
Luke	Male	29	White British	None	Supported living (24-hour support)	Living with 7 females and 5 males

Table 6: *Support Worker Demographics*

Pseudonym	Gender	Age	Ethnicity	Religion	Hours of support per week provided	Length of time supporting service user
Donald	Male	58	White British	Christian	13 hours	2 years
Carida	Female	56	Mixed Caribbean	Baha'i faith	5 hours	2 years
Emily	Female	37	White British	None	6 hours	8 years
Sally	Female	50	White British	None	3 hours minimum	8 months
Robert	Male	40	White British	None	6 hours	2 months

Table 7: *Service User and Support Worker Dyads*

Pair	Service user	Support worker
Pair 1	Johnny	Donald
Pair 2	Thomas	Carida
Pair 3	Noah	Emily
Pair 4	Matthew	Sally
Pair 5	Luke	Robert

Materials

Study materials (information sheet, consent form, demographics questionnaire, and interview schedule) were co-developed with a male service user to ensure their accessibility for participants with ID. A male co-researcher (an Assistant Psychologist working with the academic supervisor in an ID service) was recruited to collaborate on the development of the interview schedule, to mitigate the impact that an all-female research team may have on data collection. The lead researcher and male co-researcher also role-played an interview, leading to changes to the interview schedule to try to manage the incongruent interviewer-interviewee dynamic (Broom et al., 2009). For example, openly acknowledging the issue of interviewer gender and asking participants if it is difficult being asked certain questions by a woman.

In line with the IPA interviewing approach (Eatough & Smith, 2017; Smith, 1995), open-ended and non-directive questions were asked initially (Willig, 2013, p.261), followed by more specific prompts to encourage elaboration and enhance understanding of interview questions. For individuals with greater communication needs, a choice of options was presented. This is demonstrated in the following transcript extract:

Interviewer: *And so you like rugby… do you think that rugby is a manly activity or a womanly activity or something else?*

Luke: *It's erm manly.*

Interviewer: *Manly. And tell me why you say that Luke?*

Visual prompts were also available to use if needed, to enhance understanding of relevant concepts (Willig, 2013), for example, gender identity.

The transcripts from the first and second interviews were discussed with the supervisors and male co-researcher, and the interview procedure revised accordingly. Amendments included using broader prompts initially (such as "Can you tell me more?") before following up with more closed questions and offering more frequent breaks to participants. The order of the interview topics was also changed. Additional questions about participants' interests were added at the beginning, to allow participants to relax into the interview before discussing predicted sensitive topics, then returning to more comfortable topics at the end (Appendix I) (Smith et al., 2009).

Procedure

Before recruitment commenced, ethical approval from Royal Holloway University of London Ethics Committee (Appendix E) was granted. Prior to interview, the lead researcher conducted screening interviews with the participant dyads via video call to check they met the inclusion criteria, talk through the study information sheet, and obtain informed consent. Service user participants were asked to consent to their support worker discussing their gender identity with the researcher. Service users' understanding and retention of information relating to confidentiality and interview procedures was checked verbally, and all participants were deemed to demonstrate capacity to consent (Mental Capacity Act, 2005). All participants who attended a screening interview agreed to continue participation in the study. Interviews were then arranged for a later date.

Interviews varied in length between 43 minutes and 106 minutes (average of 69 minutes) and were carried out between September and November 2020. Interviews took place via Zoom video conferencing platform and were audio-recorded using a Dictaphone. During interviews, participants were reminded that they could say as

much or as little as they wanted to in response to questions. Debriefing occurred after interviews, including consideration of whether any resources from our debrief pack of information on gender identity and related topics might be helpful. At this point, once the service user had a better understanding of the interview questions that their support worker would be asked, we affirmed consent for both members of the dyads to participate. Interview recordings were then transcribed verbatim and anonymised. All participants reported that the interview was a positive and enjoyable experience.

To manage issues around confidentiality related to dyadic interview analysis (Gumede et al., 2019), pseudonyms were used, any identifying information within quotes was amended or broadened, and some quotes were not linked with a particular participant to prevent identification (Eisikovits & Koren, 2010).

Data Analysis

Our aim to achieve an idiographic analysis of individual experience fits well with the key philosophical underpinnings of IPA: idiography and hermeneutic phenomenology (Harper & Thompson, 2011; Smith et al., 2009). IPA does not attempt to develop an account of commonality across experience or determine whether participants' perceptions are in line with an external 'reality' (Willig, 2013, p.288). This contrasts with grounded theory, which aims to build a theoretical-level explanation of a phenomenon and is often the main analytical method considered in competition with IPA (Smith et al., 2009, p.196).

IPA is characterised by a set of common processes which are used flexibly. The stages of analysis outlined by Smith et al. (2009) were followed in this study as below:

1. Reading and re-reading of one interview transcript.

2. Detailed line by line analysis of the transcript in Microsoft Word, noting descriptive, linguistic, and conceptual comments in the right-hand margin of the page. The researcher used a reflective journal to 'bracket off' initial interpretations (Biggerstaff & Thompson, 2008; Finlay, 2008).
3. Emergent themes were developed from the initial noting and recorded in the left-hand margin.
4. A concise summary of the participant's story was created, detailing key pieces of demographic information and elements of the transcript that stood out. These summaries facilitated the reduction of the data whilst maintaining a link back to the original accounts throughout the analysis process (Smith et al., 2009, p.91-92).
5. The above stages were repeated for each interview. Emergent themes were then identified within each dyad, before moving on to support worker and service user participant groups (Larkin et al., 2019).
6. Themes were then clustered together into an initial framework of superordinate themes. Analysis moved iteratively between transcripts and the evolving thematic structure, to ensure superordinate themes remained grounded in participant accounts.
7. Interview transcripts were then coded into this initial thematic framework using QSR's NVivo 11 data analysis software, which helped to organise the vast amount of data (Smith et al., 2009, p.80).
8. A framework matrix was developed in NVivo, detailing the recurrence of themes across cases and including quotes that illustrate each theme (see Appendix K). This enhanced collaboration between the research team around revisions to the thematic framework and facilitated dyadic interview analysis

by visually representing patterns within and between dyads (Larkin et al., 2019).

Methodological Integrity

High quality standards of analysis were ensured through adherence to published guidelines for qualitative research (Elliott et al., 1999; Smith, 2011; Yardley, 2000):

a) Owning one's perspective through disclosure of the researcher's values and assumptions, supported by a reflective log (Appendix N) and supervision discussions.
b) Situating the sample by reporting anonymised participant demographic information (Table 5 and 6).
c) Analyses are presented coherently to achieve a sustained narrative that adheres to the theoretical touchstones of IPA (phenomenological and hermeneutic). Extracts from interviews are used to demonstrate that the themes are grounded in the raw data. Interpretations are conveyed as possible readings and any claims made are appropriate to the sample studied.
d) The use of multiple credibility checks throughout the analytic procedure to ensure credibility of interpretations. The lead researcher and academic supervisor each coded a portion of two randomly selected transcripts (one service user and one support worker account) and compared and discussed emerging themes and interpretations. Due to the high level of agreement, the lead researcher independently coded further transcripts. Preliminary themes were reviewed and

refined in collaboration with both supervisors. Respondent validation was also sought. An easy-read summary of the study themes was emailed to all participants to give them the opportunity to verify whether the themes capture their experience.

Reflexivity

IPA acknowledges that the researcher's own perspective is inevitably implicated in understanding participants' experience (Willig, 2013, p.289). The lead researcher is a white British, 31-year-old female trainee clinical psychologist, with experience of working clinically with young men with ID. This experience enhanced her interest in and understanding of the challenges discussed by participants. However, the researcher reflected on the impact her experience might have on her ability to maintain objectivity throughout the research process, using a reflective journal to consider why certain parts of transcripts stood out to her above others.

The lead researcher was mindful of her 'outsider' position to the group being studied (Dwyer & Buckle, 2009), as a woman without ID, recognising the costs and benefits of holding an 'outsider' versus 'insider' status as a researcher. For example, reflecting on the interview power dynamic, the researcher was conscious that interviewees may feel that their dyadic relationship was being judged, or their knowledge about gender identity being tested. To mitigate this, participants were assured that there were no right or wrong answers, and the study was focused on their personal experiences.

Results

Analysis of the interviews yielded three master themes reflecting prominent concepts related to the research questions across participant accounts. The master themes and the sub-themes of which they are comprised are shown in Table 8. Long extracts from interviews were shortened when necessary ("……..." indicates where text has been removed).

1. Understanding of Gender and Identity

Young men with ID held some compartmentalised views of the differences between men and women, however, more liberal views were also expressed. Most service users perceived that people of both genders can do and wear whatever they would like to, overriding stereotypical gender norms.

All service users identified as men, and this was associated with a positive self-identity for all participants. Service users worked hard to fight the vulnerability associated with the ID identity by presenting themselves as capable and independent, which they perceived to be masculine qualities. Support workers perceived that the ID identity can overshadow the masculine identity.

1. 1 Compartmentalised view of men and women

Service users focused predominantly on physical characteristics to differentiate men and women:

> I would say I'm a man! …… My underwear department is different to a woman's… errrrm… [long pause] I have a lot more facial hair than a woman! …… I don't have any big lumps on my chest! (Noah)

Table 8

Master and Subordinate Themes

Theme	Sub-themes
1. **Understanding of gender and identity**	1. Compartmentalised view of men and women 2. The meaning of masculinity 3. Contrast between masculine identity and ID identity
2. Barriers to support with developing gender identity	1. Trust 2. Practical barriers 3. Lack of gendered support 4. Barriers to independence and individuality
3. Facilitating factors to developing gender identity	1. Trust, familiarity and understanding 2. Support with social/emotional skills (not just practical) 3. Support preferences 4. Promoting independence 5. Promoting individuality

Service users held some compartmentalised (and often stereotypical) views of men and women. Matthew felt that men and women have different interests and hobbies:

Matthew: *[men and women]* do different things like differently, I've noticed …..... They *[women]* go to spas. Pampering. They sometimes go out together …….. Sometimes go out for lunch together or have a coffee somewhere.

Interviewer: And what kind of activities do you think men like doing?

Matthew: Like sport activities. Like going to the gym … Erm, going out with their mates …….. Like *[to]* the pub or something.

However, most service users also held some conflicting views around gender roles, ignoring societal stereotypes. Johnny (service user) felt that "boys can also enjoy ballet if they choose to do it. …… There's no wrong or right answer about joining a ballet group if you are a boy." Noah (service user) discussed that he likes watching both men and women play rugby. He perceived that all of the activities he enjoys are both masculine and feminine, because anyone can do them.

1.2 The meaning of masculinity

All service users strongly expressed that they like being a man, and being a man is important to them. Two service users discussed that they like being a man because this is what is familiar to them and they are happy with the way they are: "I think I just like being a man, it's what I was brought up to be. I think that's the only reason why I just like being a man" (Johnny).

Robert (support worker) noted that Luke strongly values being part of his local rugby club, which helps him to express his masculinity:

I mean that is kind of a stereotypical lads kind of place and banter I think erm, and it's all built around rugby and being kind of strong and athletic and that

kind of stuff, erm, so I think they would very much reinforce that kind of masculine side of being a man for him definitely (Robert)

This also came through in Luke's interview. Luke enjoys stereotypically masculine activities, such as watching football games, and going to pubs and nightclubs to drink beer. Luke explained that he loves rugby because he meets up with his "mates" and is part of a team that is "manly".

Service users also perceived helping and providing practical assistance to others to be an important part of their masculine identity:

Interviewer: And when you were growing up, what kind of thing told you that you were a man and not a woman?

Luke: Erm, erm, I wanted to help the girls.

Luke also believed that the activities he does with his support worker are masculine because he helps to put the equipment away. Matthew thought that being a man means being "someone helpful. …….. Being a gentleman, and if someone needs something doing, I would help them do it".

Two service users associated masculinity with being able and skilled, for example, perceiving football to be a manly activity because the players are "nice and they train really well" (Matthew). Luke felt that men and women are different "because they, erm, more skills, more smart and clever more men". An association between overcoming challenges and masculinity was also prominent in most participant accounts:

He sees himself as a man and he likes the challenges of that. …….. He wants to take on, you know, go mountain biking at one o'clock, something like that… and he likes the idea of speed and bumps in the terrain and all these

sorts of things… it fuels that slightly macho thing of, you know like, being able to cross a river with rocks on and stuff like that (Donald)

Participants associated independence and invulnerability with masculinity. Sally (support worker) perceived that Matthew expresses his masculinity through wanting to do things without support (such as going to the pub or to work independently):

When he says "no it's OK I know what I'm doing", that's when I see a lot of his masculine side …… or when he says "I don't want to talk about it, it's OK, I don't want to talk about it. (Sally)

This also came through in Matthew's interview. He was clear that he does not like talking about private matters and associated self-sufficiency with masculinity:

Interviewer: Do you think that you could talk to Sally about being a man if you wanted to?

Matthew: I probably won't. …… Because it makes me feel uncomfortable talking about myself in that way. …….. Because sometimes I like to keep things private.

Similarly, Luke associated his preference to "keep myself to myself" with being "a man". Noah also perceived invulnerability to be masculine:

Interviewer: Noah, do you think your culture influences how you show that you are a man?

Noah: Definitely. But I can't tell you exactly how. But very British. Very stiff upper lip.

This also came through in Noah's support worker's interview:

> Yeah he's definitely got that laid back kind of "what will be will be". If it can't be fixed with a beer or a hammer, then you can't stress over it sort of thing *[laughs]* (Emily)

1.3 Contrast between masculine identity and ID identity

Support worker accounts highlighted the vulnerability associated with the ID identity. Experiences of discrimination, bullying, and abuse were described. There was the sense that service users wanted to hide their vulnerability and present themselves as capable and not in need of support. Emily perceived that Noah wants to present himself as 'happy-go-lucky' to people he does not know well. When Noah became more familiar and comfortable with Emily, he dropped this "façade" and revealed his vulnerable side:

> He appears to be very strong and, I dunno, he's just a very big character, but when you get to know him he's really not like that, he's a lot more, erm, a lot more nurturing than people would expect. (Emily)

Service users discussed their identity as men but did not refer to limitations associated with ID:

> Interviewer: OK, and what kind of things does Lucy help you with?
>
> Luke: Erm, just erm, go out.
>
> Interviewer: Does she give you any help at home?
>
> Luke: Erm, she's trying to, but I'm not letting her.
>
> Interviewer: *[both laughing]* What does she try to help you with?

Luke: Erm, washing the pots.

Interviewer: And why don't you let her help you?

Luke: I will do it myself…

Donald (support worker) perceived that, for Johnny, his identity as a man is more prominent than his ID identity:

> Erm, I think he sees himself as normal. He doesn't see himself as an outsider. Erm, he does everything he wants to do within his circle, that sort of thing… he's got, you know, his girlfriend, he's got leisure time, he does things around the house, you know, works with the family, enjoys holidays… He doesn't see himself as, you know, needing special attention. (Donald)

However, support workers discussed how the ID identity can overshadow service users' identity as young men:

> So I don't think probably a lot of people do perceive him as being - and again it goes back to that thing of can he, or do people think he can, do the things that other adults can do, and is that the benchmark of being defined as being an adult man or an adult woman, that form of independence or being able to go and do this that or the other without a barrier. (Robert)

Four support workers described the men they support as loving, caring, and empathetic, contrasting with stereotypical ideas around masculinity. Carida described that Thomas is "a gentle caring man, and you don't have too many models like that without disability *[laughs]* that can be expressive of their emotions. I think his disability allows him to be expressive".

2. Barriers to Support with Developing Identity

Barriers to support with developing identity were identified across interviews, including a lack of opportunity to build trusting relationships with service users and consequent difficulty navigating their privacy. ID services prioritise support with practical daily living skills above emotional/social support, hindering conversations that facilitate the development of identity. Furthermore, the predominantly female workforce in ID services translates into a lack of male role models for men with ID. Conflict between supporting service users to find a valued place in society and supporting them to express their individuality was highlighted.

2.1 Trust

All support workers emphasised that it takes time to build a trusting relationship with service users. Emily noticed that her relationship with Noah has "definitely changed over the years, I would say, I mean… before we wouldn't have the kind of conversations we do now …… But yeah I think the more 1:1 I do with him…". Changes in staff and a lack of 1:1 time may mean that service users are more likely to turn to family members than staff for emotional support. Sally felt that Matthew will "automatically talk to his Mum first, and then we get to know about it afterwards …… he won't immediately open up to us, he'll go to his mother". This also came through in Matthew's interview, who explicitly stated he "probably won't" talk to his support worker Sally about more personal or private matters and prefers to talk to "Mostly sometimes my Mum or Dad". Emily (support worker) observed that if less familiar staff are on shift Noah is less likely to be himself:

> If I was off and there was somebody covering my shift, I don't think he'd be quite as open. I've known him for eight years now, so I've seen it all, I've

> heard it all… but if somebody was taking my shift if I was off I think he would be slightly different with them. (Emily)

Joint support sessions with other young people in supported living can also hinder private conversations. Emily observed that "unless Noah comes off to one side and we have a private chat it's a bit hard, because his housemate is there the whole time that I'm there".

Service users acknowledged that it can be difficult to talk about sensitive topics. One service user expressed reluctance to share private information, explaining that it is "complicated" because this may be communicated in handovers between support workers. Support workers were cautious about prying or pressurising service users. They preferred to wait for service users to broach topics to avoid infringing on their privacy or making them uncomfortable:

> I see that he likes women but I can't really, I haven't dug deep enough with him to work that out with him… Because I don't overstep the mark with it, I don't bring it up unless he talks about it. (Sally)

2.2 Practical barriers

Support workers and service users mentioned barriers to engaging in varied activities, hindering opportunities for identity exploration. Group activities organised by ID services need to be safe and accessible for large groups of service users, and suitable for the service budget. Both support workers and service users mentioned the need to find activities in their local area that are cheap or ideally free to attend. Carida (support worker) discussed having a certain budget for petrol and that paying for parking can be problematic. She tried to maximise the support package budget by asking organisations if support workers can attend activities for free.

A theme throughout support worker interviews was that ID services often prioritise support with practical daily living skills above emotional/social support, hindering support with the development of identity:

> They're more focused around things like you know understanding of personal hygiene and your ability to kind of travel, understanding money, all those kind of day to day living things and independence, but it doesn't necessarily go any deeper than that erm… Again, I would imagine it's a resource thing for a lot of these services as well, I mean, they have priority levels of whether he can kind of function independently" … "but yeah I certainly think that they could do things that would help him develop and kind of understand himself a bit more. (Robert)

Two support workers discussed that their support hours were solely focused on practical support rather than leisure time, hindering their ability to get to know service users as closely. Carida's role was previously focused on securing Thomas a job, however, she is now able to spend time supporting him to find a romantic relationship, which is his main priority:

> With the lockdown as well my supervisor said it would probably be a priority for wellbeing and mental health, so she gave me the remit, which was quite interesting to be unleashed to give quality time to someone, such a beautiful thing that I hadn't been able to do before, and understand the process of quality time as well and the 1:1, when you are doing something more enjoyable than job searching. (Carida)

2.3 Lack of gendered support

Some support workers and service users noted that the workforce in ID services is predominantly female. When discussing male role models support workers

referred to family members. Thomas (service user) acknowledged that he does not have much choice regarding who to confide in about his recent break up because "there's not really anyone else, really, because they're all ladies really *[chuckles]*".

Two support workers discussed that activities provided by the support services are usually aimed to suit everyone rather than being directed more towards either gender. This potentially limits opportunities to express and explore masculinity but also avoids service users being restricted by gender normative assumptions.

2.4 Barriers to independence and individuality

Support workers tried to strike a balance between supporting service users to find a valued place in society and supporting them to explore and express their individuality. It was felt that standing out from the crowd by dressing eccentrically or questioning gender identity may cause service users additional stress, when the ID identity already creates a sense of 'difference' in their lives. Donald (support worker) felt that being a man is important to Johnny because "it's one less thing to worry about, you know, it doesn't confuse issues for him". Matthew (service user) preferred to find clothes that would help him to "fit in well", potentially prioritising this above exploring his individuality through fashion. Service user acquiescence was also noted to hinder independence and exploration of individuality:

> Yeah so I don't think he would – whether it's a thing of not wanting to upset somebody or erm, I guess that kind of might come across as being quite agreeable, erm, and then he probably wouldn't say if he wasn't enjoying something either. (Robert)

3. Facilitating Factors to Developing Gender Identity

Familiarity and trust were essential prerequisites for support with developing identity. Striving to get to know service users through conversations about their

hopes, likes, and dislikes, was highlighted as an important element of support. A sense of community was highly valued by all service users. Support with social skills and relationships was considered essential for the development of identity.

The importance of promoting independence and individuality for supporting the development of identity was a theme across support worker interviews. It was clear that service users valued making their own decisions, trying different things, and talking to a variety of people. Men with ID had some preferences for support from males or females with certain things.

3.1 Trust, familiarity and understanding

Across both support worker and service user interviews it was clear that familiarity and trust are necessary for meaningful conversations, and a close bond and feeling comfortable with staff members is prioritised over staff gender:

> We do have a male staff member, but he never seems to want to spend time with him …… because I think when you understand Matthew, he'll understand you more, and that's why he'll want to spend more time with you, because he's comfortable. (Sally)

Consequently, consistency in staff was felt to be important for enabling service users to explore and develop their identities:

> From a [support service] perspective, consistency with staff would have been better. Because with Noah, for him to talk openly and for him to take on board what people are saying, he needs to know them quite well. …… I think that might have given him the confidence to be more open about who he is and about his sexuality and things. (Emily)

Support workers noted that one-to-one time is extremely important for getting to know service users well enough to have deeper and more sensitive conversations

and support them on their journeys to becoming men: “it’s having those opportunities of allowing him to open up, and I think that’s where we need the support for him” (Sally). Support workers felt that spending leisure time with service users is more effective for getting to know them well compared to time spent supporting with practical daily living tasks. Interviews highlighted that both support workers and service users value connecting over shared interests, which strengthened their bond:

> He does like to have 1:1 time …….. and I think erm there’s people who he connects better with than others, and he will generally come up to you and say can we have some 1:1 time, and I find he does that a lot with me, because I like to spend time with him and we’ve got similar interests, so that makes a big impact, like I love music and I love theatre, so we connect. (Sally)

Support workers observed that listening, being curious, and asking open questions is important for supporting with the development of identity:

> Maybe sort of finding out what his hopes are for the future and where he sees himself and building up on that. Because we’re getting to know each other, and it’s the same for every staff member, it’s getting to know each other… But he comes to me a lot of the time, and when he does, I just embrace that, and I’ll say to him “How can I support you?” or “What do you feel?” (Sally)

3.2 Support with social/emotional skills (not just practical)

All service users valued socialising and a sense of community. When asked what he likes about rugby, Luke responded “I’ve got, erm, a team”. Service users consistently prioritised connecting with others above specific activities. Carida (support worker) noticed that Thomas is “so eager to get out of the house and go and meet someone that most of the things he’ll do just for the social engagement”. Luke (service user) was clear that he enjoys "hanging around having fun" with friends and

family above specific activities. This was also evident in Luke's support worker's interview:

> He likes this kind of being one of the lads kind of thing. …… you know the stuff with [local rugby club] …… being part of something he really cares about is really important, and is probably something he feels gives him a bit of kind of meaning in life I think, you know, and that goes for family as well – he's super close to family. (Robert)

All support workers discussed the importance of supporting service users to socialise. They felt that service users would struggle to initiate social activities or meet peers independently; however, when they are supported to do this, it has a hugely positive influence on their wellbeing:

> With Noah he needs like a little push to do things… so at the beginning of lockdown he'd made a few comments to another Buddy that he hadn't really seen anyone. And erm, I managed to arrange for two picnics when we could meet up …… And he came away *so* [emphasis added] happy from all of those. (Emily)

In line with this, service users valued support with meeting friends and perceived this to be an important part of their identity:

> Interviewer: And, would you like more support with being a man?
>
> Luke: Erm, erm, yeah. …….. go to town to meet my friends.

Support with socialising also included support with finding and maintaining romantic relationships and overcoming difficulties in friendships and social encounters. Carida (support worker) discussed that support with social skills and romantic relationships is essential for wellbeing and is more complex than providing

support with practical daily living skills. She described her experience of supporting Thomas to form a group of male friends:

> He asked me one time if we could go to see his favourite band … But then my supervisor said if I could work on him forming other relationships, so that he wasn't so dependent on a 1:1 support, because he didn't have these networks to go anywhere, he didn't have a friend to go! … so I put effort into him forming relationships, so there's a group of boys … and at the disco they tend to form a little group … and when their song comes on, they would get up on the stage together … just the boys. (Carida)

2.3 Support preferences

A theme of consistency in support from male and female support workers was prominent in the interviews. All service users reported that the same activities are suggested by male and female staff, and generally did not perceive support from males and females to be different. Support staff were also in agreement with this: "I would say there's no difference – Sam and I, we're the two that support him, and we're very much on the same page" … "I don't think Sam and I work that differently with him" (Emily). However, some support workers felt that although the support provided by men and women is not particularly different, it can be beneficial for men with ID to spend time with male staff of a similar age to them "because male support workers are fewer, and particularly young ones as well are fewer so erm they're good for modelling" (Carida).

All service users described that they do not change their behaviour around staff of different genders:

Johnny: I don't know why I enjoy it, but I just enjoy being around people, no matter what gender they are …….. I just enjoy being around people.

Interviewer: …… and do you change how you act if they are a different gender?

Johnny: No. I just be myself.

Both men with ID and support staff perceived that feeling comfortable with the support worker was prioritised by service users above the gender of staff. Noah (service user) exclaimed "I don't mind the gender at all! Honestly, don't mind at all. If they're up for a good laugh and a giggle, then I don't mind the gender".

Some men expressed a preference for support from a staff member of a particular gender for specific (and often more personal) things. However, the preferred gender of support worker varied for different participants. For example, although Matthew did not perceive support from men and women to be very different, he preferred to receive support with housework from females "Because I'm used to them, who they are". Matthew also preferred talking to female support workers about private things "Because they try and understand what you're talking about and they try and get it right". Conversely, Thomas stated a clear preference for talking to male support workers about romantic relationships:

> Because obviously I'm a young man and I just think it's more appropriate for a male support worker to come and support me, in my opinion anyway! [chuckles] …… Because if you're talking about, you know, yourself getting to know a girl or something, it's more sort of suitable, for that to be effective. If you see what I mean. (Thomas)

3.4 Promoting independence

Support workers discussed their efforts to develop service users' confidence by promoting their independence. An important part of this was making collaborative decisions by presenting service users with options and supporting them to decide how they would like to spend their time. All service users reported that they decide the activities they do and the places they go to, in collaboration with support workers. It was clear that service users found decision-making complicated and challenging and appreciated support with this. One service user referred to decision-making as a manly activity.

Interviewer: And do you chat to Sally about manly things?

Matthew: Yep.

Interviewer: What kind of things?

Matthew: About what's the best thing to do, and if I'm in a situation where I can't decide what to do.

Interviewer: Mmm, what kind of situations?

Matthew: What to do today and when.

Support workers aimed to give space for men with ID to discover their own likes/dislikes and interests, free from the influence of others. Robert wanted to ensure that Luke can explore other interests outside of rugby and sport:

> I don't want him to get into that thing of just being kind of very structured and repetitive each week … because I think it would help his development and you can explore new activities and interests… and hopefully he's then directed a bit more by the stuff that he wants to take part in and do, which would be good. (Robert)

One service user was involved in the social activities committee at his support service, attending meetings to suggest and discuss activities.

Support worker interviews highlighted the importance of providing choice and flexibility around support and activities for the development of independence and identity. Donald discussed that the support service strives to ensure that activities are not limited by staff availability or preferences. For example, organising a different 'Buddy' to do road cycling with Johnny, because he is passionate about cycling and Donald is only able to do off-road cycling with him. Support workers also aimed for service users to be able to choose which staff member to talk to about different topics: "Nine times out of ten if he opens up to a staff member and it's something deep and meaningful, they will say you know who do you want to talk to about that?" (Sally)

3.5 Promoting individuality

Support worker accounts highlighted the importance of encouraging variety and novelty in activities and conversations, for the development of service users' individuality and identity. One support service purposefully arranges for service users to work with different 'Buddies' every couple of years. Service users were also keen to try different things and enjoyed talking to different people:

> It would be nice to have a male one [buddy] as well as a female …….. because it's nice to have a change. I don't like to have the same Buddy all the time, if you know what I mean. (Thomas)

Support workers aimed to embrace service users' individuality, rather than treating them differently based on their gender: "I wouldn't say I treat people differently, you know, the males and females I support … It's not kind of, you know, it's not male and female to me, it's just individuals" (Emily). Four support workers

spoke of trying to enable service users to explore both the masculine and feminine sides of themselves. Donald discussed that Johnny has done a wide variety of activities suitable for both sexes, in mixed groups of service users, empowering him to find out what activities he likes. Sally spoke of wanting to support Matthew to be proud of who he is and was aware of not pressuring him either one way or the other in terms of gender identity or sexuality. She tried "to find ways of you know making him aware that he can embrace that masculine side, because, you know, it's not something that should be pressurised either". Emily steps back and allows Noah to express himself through unique and eccentric fashion and hairstyles, only offering opinions when Noah asks for them, and only offering advice for practical reasons:

> He's got his own style …… it's just when it gets too long and you can see it's irritating him I might say "I think it's about time to sort that now". Because he gets a lot of ear infections as well, so we try and make sure that his ears and kind of clear so that we can check on them. But not for aesthetics, it's more for sort of medical reasons and sort of comfort for him that we prompt him about things like that. (Emily)

Discussion

This study explored how men with ID understand and develop their gender identity/masculinity, from the perspective of both support staff and service users, with the aim to improve support in this area. Being a man was an important and positive aspect of life for all service users. However, support worker accounts suggested that the ID identity can overshadow gender identity, preventing service users being seen and treated as "real" men and women, in line with previous research (Mutua & Swadener, 2015; Toft et al., 2019; Wilkinson, 2013).

Study findings revealed facilitating factors and barriers to supporting men with ID to develop their gender identity. It was clear that familiarity and trust are a prerequisite for support in this area, and ID service constraints (such as changes in staff and a lack of one-to-one leisure time) can hinder the development of trusting relationships between staff and service users. Support with social skills and relationships was deemed essential for identity development, and service users valued this support highly. However, ID services often prioritise support with practical daily living skills above emotional/social support. A proactive approach to initiating meaningful conversations with service users was needed. However, support workers often waited for service users to broach topics due to concern about infringing on their privacy. Study findings highlighted the importance of promoting service users' independence and individuality, by supporting them to make their own decisions, and providing choice and variety in activities and support. However, service constraints can hinder this. Free activities that suit both genders are often prioritised. Additionally, men with ID are not always able to choose support from male staff when it is desired, due to the predominantly female workforce in ID services.

In line with previous studies, participants with ID sometimes distinguished men and women according to stereotyped gender roles (Barron, 2002; Brown et al., 2010; Groves et al., 2018). However, contrasting with existing literature, they also expressed some more liberal views, asserting that people should do and wear whatever they please without being restricted by their gender. Interestingly, participants with ID who lived in 24/7 supported living houses held notably more stereotypical views compared to participants who lived with family members or received less intensive support. This could be reflective of the fact that traditional patterns of gendered behaviour and roles are often upheld in ID services (Clements et

al., 1995), possibly producing and reinforcing gender stereotypes among service users.

Overall, support staff aimed to embrace service users' individuality rather than treating them differently based on their gender. This contrasts with the theme in the existing literature, that support providers are blind to the possibility of "norm-breaking" gender identities among service users (Björnsdóttir & Stefánsdóttir, 2020; Gomez, 2012; McCann et al., 2016; Sommarö et al., 2020). This may be reflective of the sociocultural shift that is happening more broadly. Society is now far more open and flexible in terms of gender labels and identities (Risman, 2018). However, although support workers encouraged individuality, this was balanced with supporting service users to "fit in" and find a valued place in society. Theories on the intersection of ID, gender, and sexuality are lacking. However, disability theories that incorporate discussions of gender and sexuality highlight that disability may be regarded as one type of socially defined deviance, and disabled people can experience oppression due to harmful societal attitudes about "non-normative" appearance and sexuality (Anderson & Kitchin, 2000; Cheng, 2009). Consequently, the ID identity can be a barrier to the exploration of gender identity, because people with ID have a strong desire to be considered "normal" to compensate for the stigma attached to the ID identity (Groves et al., 2018; Toft et al., 2019).

Participants with ID valued their identities as men highly, but they did not discuss the ID identity in their interviews. The disparity between how participants with ID saw themselves and how others perceived them was striking, echoing previous research (Midjo & Aune, 2018; Wilkinson, 2013; Wilton & Schormans, 2020). Men with ID resisted the vulnerability associated with the ID identity by

presenting themselves as independent and capable (Brown et al., 2010; Midjo & Aune, 2018; O'Shea & Frawley, 2020), which were qualities they associated with masculinity. A large-scale population-based study compared conformity to masculine norms among men with and without a disability and found much greater conformity to Self-Reliance norms among men with a disability, and less conformity to norms related to Pursuit of Status, Primacy of Work, Heterosexual Presentation, Risk-Taking and Dominance (King et al., 2020). The researchers hypothesised that Self-Reliance may constitute a dimension of masculinity that is attainable for men with disabilities, corresponding with gender identity theory stating that the extent to which children adopt observed gendered behaviour depends on their perceived efficacy to master it (Bussey & Bandura, 1999). On the other hand, the high conformity to Self-Reliance may indicate resistance to dependence on others and the lack of autonomy in the lives of men with disabilities (King et al., 2020), in line with other recent research with men with ID (Wilton & Schormans, 2020). A strong theme in the current study and the existing literature is the patent need for support providers to respect the importance of independence and self-reliance among men with disabilities and find means to promote this (Bjornsdottir et al., 2017; Björnsdóttir & Stefánsdóttir, 2020; King et al., 2020; Midjo & Aune, 2018; Mutua & Swadener, 2015; Wheeler, 2007; Wilson et al., 2011; Wilton & Schormans, 2020).

Support workers had trouble supporting men with ID to explore their true interests due to acquiescence, in line with previous research highlighting internalised oppression among the ID population (Groves et al., 2018). Service users valued making their own decisions but found this challenging and appreciated support with this. Other researchers have highlighted difficulty in decision-making among people with ID, hypothesising that they do not have a clear idea of how they would like to

spend their time due to lack of a clear sense of identity (Fitzgerald & Withers, 2013; Groves et al., 2018; Mutua & Swadener, 2015). This is not surprising, considering their lack of access to different contexts for exploring identity, resulting in increased dependency on others to propose ideas for how they can express themselves (Björnsdóttir & Stefánsdóttir, 2020; Mutua & Swadener, 2015; Sommarö et al., 2020). To address this issue, Stay Up Late (a national campaign and charity) developed an initiative called Gig Buddies to support people with ID to grow their social circles. People with ID are matched with a volunteer who shares the same interests and passions. Gig Buddies has been shown to help people with ID develop their self-identities by increasing awareness of different ways in which they can spend their time and increasing confidence in making decisions (Codd, 2021; Stay Up Late, 2020).

Wilson et al. (2011) found differences in gendered support around leisure time in ID services. In contrast, support from men and women was perceived to be largely consistent in the current study, according to both service users and staff. It is possible that this is because the participating support services strive to provide activities that are suitable for both genders. Despite perceiving support to be consistent generally, men with ID did express preferences for support from either a man or a woman with different (often more personal) matters. For example, one service user wanted to talk to a male support worker about dating, in line with the previous finding that male service users benefitted from support from male staff around sexuality (Wilson et al., 2011). Choice and flexibility in support is essential for promoting service users' independence and identity development (Bjornsdottir et al., 2017). However, due to the predominantly female workforce in ID services, men with ID are not always able to choose to talk to a male staff member when desired. Wilson et al. (2011)

emphasised the importance of young male service users spending time with male role models of a similar age to them, which was also expressed by a support worker in the present study. The shortage of male staff needs to be addressed in order to meet the Government's objective to enable people with ID to have as much choice and control as possible over their lives and the support they receive (Department of Health, 2001).

A clear theme in both service user and support worker accounts was the importance of supporting men with ID to make connections with others. Correspondingly, theories of gender identity development emphasise the importance of feedback from a peer group for making sense of who you are (Bussey & Bandura, 1999; Erikson, 1968). Support workers noted a clash between the type of support necessary for identity development and the priorities of ID services. Services focus on teaching independence skills rather than prioritising social relationships and emotional support, resulting in service users who are isolated and lonely (Clegg & Lansdall-Welfare, 2010; Clements et al., 1995). One support worker acknowledged that this is likely due to lack of resources and funding in ID services. Government spending cuts to adult social care budgets mean that funding is being spent on what is considered crucial, for example, housing or medication needs, rather than supporting people to socialise and lead full lives (TED, 2017) This is concerning, considering the devastating impact of loneliness on health (Valtorta et al., 2016), and is a direct betrayal of the Government's promise of a commitment to fairness in society (P. Richards, personal communication, April 28, 2021). Furthermore, evidence shows that increased spending on social care decreases the amount that needs to be spent on healthcare, yet social care is vastly underfunded in comparison to healthcare (The Kings Fund, 2010).

Given that the interviews were conducted during the pandemic it feels important to reflect on the themes in the context of Covid-19. Support workers discussed obstacles to the provision of support due to the pandemic, and the impact of the pandemic on service users' usual group activities and social isolation. One support worker discussed that ID services have increased their focus on mental health and wellbeing since the pandemic. At the beginning of the analysis process, the impact of Covid-19 was a standalone sub-theme, however, this was later removed as the thematic framework evolved because the content was deemed less relevant to answering the research questions. The theme pertaining to the importance of supporting service users to socialise and connect with others was not weakened when the pandemic sub-theme was discarded.

Clinical Implications

The facilitators and barriers to supporting men with ID to develop their gender identity translate into key clinical recommendations that will be disseminated to ID services (see Appendix P). The striking disparity between how people with ID see themselves and how society perceives them has implications for the development of a valued identity. Reflective spaces for staff may be crucial in maintaining awareness of any limiting assumptions, such as the focus on the ID identity above gender/other identities more valued by service users.

Study findings indicate the importance of a proactive approach to meaningful conversations that facilitate identity development. However, support staff lacked confidence in broaching sensitive topics whilst also respecting service users' privacy. Service users also expressed concern about opening up to support staff, worrying that sensitive and personal information can be communicated in staff handovers. This

suggests a training need around sensitive conversations among service providers. Organisations like Mencap have developed useful resources to support conversations around gender identity and embracing individuality with individuals with ID (Mencap, 2020), which could help to increase confidence amongst staff. Services may also benefit from updating their guidance around information sharing, to include the need to collaborate with service users about the pros and cons of sharing information in handovers. Open conversations with service users should be a priority, and people with ID should be supported to understand the concept of continuity of care and why certain information is shared.

The predominantly female workforce in ID services may have some negative implications for male service users. There is a need to boost the recruitment of men to ID services, by recognising and encouraging the unique contributions of male staff; increasing full-time posts and opportunities for career progression; and reducing the stigma associated with men who undertake caring roles in British society (McConkey et al., 2007). The perception that male support workers are “unmasculine”, and accusations of abusive motivations for undertaking the work must be addressed, to create ID services that foster positive outcomes for male health and male expression (McConkey et al., 2007; Wilson et al., 2011).

A major shortcoming of current policy informing ID services is failure to improve social relationships (Clegg & Lansdall-Welfare, 2010). Services must undergo cultural change, away from a focus on ‘lonely self-sufficiency’, to address the yearning to belong that people with ID share with the rest of mankind (Clegg & Lansdall-Welfare, 2010). ID support services should be a community in and of themselves, fostering connection between staff and service users, to address the

isolation and stigma experienced by people with ID and those who support them (Clegg & Lansdall-Welfare, 2010; Clements et al., 1995). Current Government programmes emphasise the need for health and social care to ensure that people are supported to have meaningful everyday lives, including support to develop and maintain good relationships (Building the Right Support, 2015; Transforming Care 2015). It is recognised that to achieve this, staff need to have the right skills (Building the Right Support, 2015), and psychological-mindedness should be promoted across the ID workforce (Clegg & Lansdall-Welfare, 2010). Specialist supervision and consultation from Psychological services could be beneficial. For example, the Stay Up Late charity provide tailored ID awareness training, co-delivered by a trainer with ID, covering topics such as how to support people in a way that truly appreciates them as a person beyond their diagnosis; how to support people in a way that is truly led by them (including advice on setting up advisory groups); and how to meaningfully involve people with ID in the process of staff recruitment (Stay Up Late, 2018).

Finally, internalised oppression and stigma can hinder the promotion of independence and individuality among men with ID, because service users are so focused on "fitting in". Service providers should be vigilant to acquiescence among the ID population and create environments in which they feel empowered to speak for themselves (Bjornsdottir et al., 2017). Service users must be supported to make decisions about their everyday lives, with accessible information to support this process. Service managers should implement a formal process for receiving regular and ongoing service user feedback, ensuring that support is in line with the lifestyle service users want. The stigma around the ID identity must be tackled, to ensure that people with ID are not restricted from embracing their individuality and exploring

"non-normative" gender identities (Scior & Werner, 2016; UCL, 2021). Increased LGBTQ+ support groups and advocacy services are likely to be important in achieving this. It would also be beneficial for support staff to have open conversations with service users about what disability means and address any misinformation (Groves et al., 2018).

Strengths and Limitations

To the authors' knowledge, this is the first dyad study to explore the intersection of masculinity and ID from the perspective of men with ID and their support workers. Dyadic interview analysis was a key strength of the study, enhancing understanding of the fundamentally important relationship between support staff and service users (Eisikovits & Koren, 2010). However, there are challenges associated with dyad study designs. For example, despite assurances of confidentiality it is possible that participants felt a loyalty to the other member of the dyad and did not feel able to voice more negative views (Gumede et al., 2019). A longitudinal study design with repeat interviews may have mitigated this by allowing trust to develop between the researcher and participant (Gumede et al., 2019); however, time restrictions associated with the research did not allow this.

A further strength of the study was the even number of male and female support workers in the sample (two men and three women), despite the shortage of male staff in ID services. However, there may have been a bias in the sample in terms of who volunteered to participate in the study. Two support workers expressed a particular interest in the topic and were making a personal effort to undertake further training, and two service users in our sample had "norm-breaking" sexual identities. This indicates that participants may have experienced fewer barriers to talking about

gender identity, or personal and sensitive topics more broadly. There was also a lack of ethnic diversity in our sample, preventing understanding of how ID and male identities intersect with minoritized ethnic identities. The purposive sampling method (including the selection of participants with ID who were able to participate verbally in interviews) enabled a homogenous sample that is beneficial for IPA. However, this limits the generalisability of the findings and meant that the study did not capture the experiences of those with more severe/profound ID. Nevertheless, although we hoped to identify themes that may be generalisable to the wider population of men with ID, the aim of this study was to explore these themes in-depth within our specific sample.

A complex issue during interviews with participants with ID was the need to address the power imbalance in the researcher-participant dynamic. It has been noted that both gender congruence and gender incongruence (in terms of the interviewer-interviewee relationship) have advantages and disadvantages (Broom et al., 2009). Some argue that gender congruence can facilitate rapport, however, it has also been found that male interviewees are more comfortable discussing sensitive and personal topics with a female researcher (Lohan, 2000; Williams & Heikes, 1993). Researchers have debated the disadvantages of women interviewing men and expressed concern that the power of the male interviewee's masculinity may overthrow the female researcher, resulting in an imbalance where the interviewee takes control of the interview process (Broom et al., 2009). This would arguably be less of a problem in research with male participants with ID because people with ID are inevitably in the lesser position of power regardless of interviewer/interviewee gender. In fact, the gender-incongruent interview dynamic may even be an advantage, to address the powerlessness associated with the ID identity.

It is possible that a female interviewer asking questions about masculinity compromised the validity of the data collected. However, consultation with a male service user on the development of the topic guide; feedback from our male co-researcher on the interviewing technique; and feedback from participants with ID when debriefing after interviews suggested that the interview process was comfortable and non-threatening. Furthermore, it has been argued that the pressure that male interviewees may feel to enact cultural ideals of masculinity and hide key issues faced by men is a problem in the context of both female and male interviewers (Broom, 2004; Broom et al., 2009). Despite this, an all-female research team may have interpreted the data differently than male researchers, therefore, gender may have been a limitation to the analysis process.

During interviews with men with ID, it is possible that attempts to facilitate understanding (using prompts and fixed choice questions) may have compromised the open and non-leading interviewing technique that is conducive to IPA studies. The interviewer tried to mitigate this and counteract acquiescence by reminding participants frequently that there were no right or wrong answers and emphasising interest in their personal views.

Future Research

More research is needed to explore what an environment where maleness is positively valued might look like. This should include asking men with ID about their support needs and preferences; exploring the unique contributions of male support staff; and evaluating attempts by service providers to boost male participation in their workforce (McConkey et al., 2007). It would be informative to analyse efforts to enhance relationships between support staff and ID service users, including the impact

that more male staff and a greater focus on social/emotional support within services has on the identities and wellbeing of people with ID. It could be interesting to compare support with gender identity development for people with ID in different living environments; for example, the relationship between a support worker and service user in a residential service is likely different to supportive relationships developed via day services. Future studies could use inclusive research designs and involve co-researchers with ID at various stages of the research process, to build on and enhance the themes found in non-inclusive literature. This would ensure that the research is truly meaningful and useful to the population with ID (Walmsley et al., 2018). It would also be helpful for future research to strive to give voice to those who are under-represented in the literature, such as people with more severe/profound ID and people from minority ethnic backgrounds.

Conclusion

Being a man was an important and positive part of life for men with ID and fostered the development of a valued self-identity. The ID identity was a barrier to the enactment of masculinity. Trusting relationships with staff, and support with social relationships and emotional skills, are fundamental to identity development. However, ID services often prioritise the promotion of independence and practical daily living skills. The wellbeing of men with ID can be enhanced by supporting them to embrace their individuality and make meaningful choices around support and activities. Unfortunately, this can be hindered by stigma; internalised oppression and the consequent difficulty service users experience in making their own decisions; the limited resources of services; and the shortage of male staff. This needs to be addressed in order to meet the Government's objective to enable people with ID to

have as much choice and control as possible over their lives and the support they receive (Building the Right Support, 2015; Transforming Care 2015).

Paper 3: Integration, Impact, and Dissemination

This paper critically reviews (a) my experience of conducting the research and the integration of papers 1 and 2 into a unified whole; (b) the potential impact of the findings and how these can be maximised; and (c) plans for dissemination of the findings.

Integration

Interest in the Research Topic

I was drawn to the Embracing Gender Identity project led by Dr Karen Dodd because the aims and objectives of the research resonated with my longstanding interest in the barriers to leading a full and "ordinary" life for young men with intellectual disabilities (ID). This interest was developed through my role as an Assistant Psychologist in an adult ID service, which involved my first experiences of 1:1 clinical work and confirmed my passion to undertake clinical training. Memories of therapy sessions with a young man with ID have particularly stayed with me. I was struck by the barriers to socialising and enacting normative masculinity he faced due to infantilisation and overprotection. The young man yearned for social contact, however, due to lack of support to meet peers he was entering risky situations and being taken advantage of by undesirable people he met via Facebook. This risk was managed by the service that supported him by monitoring his social media access and not allowing him to go out on his own, impeding his sense of autonomy and increasing his desire for leisure time with and attention from support staff. Due to service constraints and the priorities of staff this desire was not met, resulting in behaviours that challenge and further fracturing of the relationship between the young man and his support workers. This piece of clinical work led to consultation with the

young man's support network to increase understanding of his needs and behaviour, highlighting the nature of the systemic maintenance of "individual" problems to me. I enjoyed exploring and understanding the young man's perspectives and advocating for his voice to be heard, which aligned well with the aims of this research project to generate detailed understanding of individual experience and give voice to the marginalised population with ID. Furthermore, my prior experience of conducting and publishing qualitative research drew me to the project. I was hopeful for the opportunity to broaden my experience of using different methods of qualitative analysis.

The topic for the systematic review directly complemented the empirical study. I hoped it would offer greater context around some of the experiences discussed by empirical study participants, and that both papers would enable improved understanding of the support needs of men with ID.

Choice of Data Analysis

The decision to use interpretative phenomenological analysis (IPA) was informed by the research questions and the aim to gain detailed interpretative accounts of individual experience (Smith & Osborn, 2015). I initially felt concerned that although small sample sizes are known to be beneficial for IPA research, this may be queried by research approval committees and could be considered by non-qualitative researchers to be too unsophisticated for a doctoral thesis (Wagstaff et al., 2014). On the other hand, being aware that IPA is "easy to do badly and difficult to do well" (Larkin et al., 2006, p.103), I experienced apprehension around balancing the in-depth and time-consuming analysis process with the time restrictions associated with doctoral research projects. Additionally, due to the focus on language (for

example, the use of metaphors) in IPA (Pietkiewicz & Smith, 2014), I initially considered whether IPA would be an appropriate method for a research sample who may be linguistically limited. However, there is convincing evidence demonstrating that IPA is an appropriate method to use in research with the ID population (Rose et al., 2019). Due to the idiographic focus of the study, I was convinced that IPA was the most suitable approach for analysis.

A mixed-methods approach to the systematic review was chosen with the aim to maximise the relevance of the findings and their ability to impact policy and practice (Harden, 2010). The decision to use thematic synthesis for analysing the qualitative review data was informed by the research questions, the type of data being reviewed, and the aim to 'go beyond' the primary studies and generate interpretive explanations (Thomas & Harden, 2008). Thematic synthesis draws on Noblit and Hare's (1988) well-established meta-ethnographic method of qualitative synthesis. It has been recommended that thematic synthesis is more appropriate for addressing a specific review question to inform policy and practice, whereas the meta-ethnographic approach is preferable for exploring a body of literature and allowing review questions to emerge (Thomas & Harden, 2008). Due to the review aim to elicit barriers and facilitators to support with gender identity development and inform clinical practice it was agreed that thematic synthesis best suited the research questions.

Reflective Journal

The theoretical underpinnings of IPA, interpretative phenomenology and hermeneutics, posit that completely separating ourselves from our assumptions is not possible and therefore we must reflect on the influence these will have on the research

process (Langdridge, 2007, p.55). IPA involves a ‘double hermeneutic’ (Smith & Osborn, 2015), therefore it is necessary to reflect on the researcher’s own position; the position of the participant; and the process of the researcher trying to understand the participant’s position (Montague & Holland, 2020). The use of a reflective journal helped me to be aware of my preconceptions, to ensure they did not impact the rigour of the research (Finlay, 2008). The journal was also used to record decisions around planning and conducting the research and is the source of much of the content of this paper.

Ethics and Recruitment

I submitted my ethics application towards the beginning of the Covid-19 pandemic, including a contingency plan to conduct interviews via video call. The pandemic meant that this contingency plan was followed. Consequently, all service user participants identified by service managers were familiar with Zoom video conferencing software, potentially excluding people who are less confident with technology and leading to a bias in the sample. Considering the growing problem of the ‘digital exclusion’ of people with ID this may be a significant limitation to the study (Low Incomes Tax Reform Group, 2012). Furthermore, unfortunately we were unable to recruit an ethnically diverse sample. All participants were White British, other than one support worker who was Mixed Caribbean. It is likely that the meaning and expression of masculinity differs across cultures, therefore the findings of paper 2 cannot be generalised to people with ID and their carers from different ethnic backgrounds.

Conducting the Interviews

Before the first interview I felt nervous about potential internet connection issues and the impact on rapport and being able to hear the interviewee clearly. It was agreed that if issues arose, I would use telephone rather than video call as a last resort. However, I was concerned about this being less accessible for participants with ID due to lack of option to use visual prompts. Telephone may also have hindered my ability to understand participants clearly due to not being able to see their faces. Thankfully, I was able to use video call for all interviews, and this afforded some unforeseen advantages. Participants may have felt more comfortable due to being able to take interview coffee breaks in their own homes. Research has shown that patient comfort and the therapeutic alliance are not compromised in 1:1 video call therapy compared to in-person therapy (Jenkins-Guarnieri et al., 2015), in line with the experience of the research interviews from my perspective. If interviewees felt more comfortable this may have reduced acquiescence.

Prior to the pandemic we had planned for our male co-researcher to be involved in conducting the interviews. However, it was agreed that the pros of having a male co-interviewer would be outweighed by the cons of having a more confusing and potentially more awkward interview dynamic via Zoom. This concern is substantiated by evidence that patient comfort can be compromised when group therapy is delivered by video call compared to in-person (Jenkins-Guarnieri et al., 2015). Nevertheless, without the complication if the pandemic, the study may have benefitted from a more inclusive approach to the research, such as the involvement of a co-researcher with ID in conducting the interviews. This may have enabled interviewees with ID to speak more openly about their experiences (Walmsley et al., 2018). However, a more inclusive research process would have come with its own

limitations and challenges, such as less control for the lead researcher over the interview process and fidelity to the topic guide. It has also been suggested that the participatory paradigm can complicate writing up for publication in journals, therefore more creative forms of dissemination such as films may need to be explored (Beail & Williams, 2014; Haigh et al., 2013).

When transcribing the first interview I felt concerned that my lack of experience working in an ID service as a trainee clinical psychologist may have caused me to miss relevant prompts or hindered my ability to instinctively ask insightful follow-up questions. My supervisors and our male co-researcher read the transcripts of the first two interviews and offered encouraging feedback and helpful suggestions around the interview questions and technique. For example, being led more by participants' own language ("Do you usually call yourself a man? Or a boy?") and prompting about different types of support (such as personal care, private conversations, leisure activities) when asking about support preferences. We also discussed that I often did not sit with silence during interviews, due to striving to ensure that participants were comfortable. However, this could impede opportunities for participants to reflect and add more information and at times hindered the clarity of my questions. In subsequent interviews I was mindful of this, informing participants at the beginning that I would be pausing to think about my questions and the best way to ask them.

Coding and Analysing the Empirical Data

During the analysis process I felt overwhelmed by the amount of data, and was comforted to know that this is considered a defining experience for phenomenological researchers (Nolan, 2011). I found myself resisting the focus on the common themes

derived from the idiographic data, worrying that they would overshadow the richness of individual experiences. Other researchers have also noted the tension between the idiographic focus of IPA and the development of common themes (Nolan, 2011; Wagstaff et al., 2014; Wagstaff & Williams, 2014). Dropping themes because they appeared less often felt uncomfortable, in case they were crucial for a particular participant. However, my use of participant summaries (see Method section, Paper 2, p.80) helped to maintain a link back to original participant accounts during the analysis process.

When planning my steps for analysis, I read researcher discussions on an online IPA forum (Groups.io, 2021) and attended an IPA training workshop (Montague & Holland, 2020). Drawing on the previous experiences of other researchers, I decided to analyse the data by hand using Microsoft Word, using NVivo software subsequently to manage the sheer volume of data and visualise patterns between themes using a framework matrix (QSR International, n.d.). I found the framework matrix particularly helpful for dyadic interview analysis and selecting participant quotes, however, this was offset by the duplication of effort when coding the data for a second time (first in Word, then in NVivo).

Respondent validation was used to ensure the credibility of the findings; however, no participants responded to offer their feedback. It is possible that the pandemic hindered this process, because I was prevented from visiting the participating services and participants were contacted twice by email instead.

Synthesising Systematic Review Findings

I found the process of developing and refining themes more challenging for the systematic review compared to the empirical paper. This was likely due to the broad range of research questions and aims of the 17 included qualitative studies. There was significant overlap between themes, yet the findings of different studies could also contradict each other at times. (For example, the finding that people with ID are more used to thinking of themselves as intellectually disabled than as "proper" men and women, versus the finding that people with ID do not have a good understanding of what disability means and do not identify closely with the ID identity). As with the empirical paper, there was the challenge of developing common themes without losing the essence of the primary studies. Furthermore, due to lack of clear guidance for synthesising data for mixed-methods reviews (Hong et al., 2017; Petticrew et al., 2013), the process of writing up the Results felt quite disjointed, and I worried whether I was doing this correctly. Supervision was valuable for reviewing and clustering candidate themes.

Areas of Concordance and Discordance

Both papers focused on how people with ID understand their gender identity and how this is or is not facilitated by their support staff, therefore the papers were easily integrated into a unified whole. Due to the limited research in this area, the systematic review included studies of both men and women with ID, whilst paper 2 focused exclusively on men with ID.

A clear and common theme across both papers was the tension between masculinity and disability, and the disparity between how society views people with ID and how they see themselves. Service user participants in both papers were eager to discuss gender identity but not the ID identity. However, support providers were

focused on ID, and the ID identity overshadowed gender identity. Both papers indicated that the ID identity can be a barrier to exploring gender identity due to "dual stigma" and the desire to be "normal" and find a valued place within society. The need to reduce the stigma around the ID identity was clearly indicated (Scior & Werner, 2016; UCL, 2021). Staff training with the aim to promote support that focuses on service users' essence as people rather than on their diagnosis as intellectually disabled could be beneficial (Stay Up Late, 2018).

Both papers demonstrated that service users resist the ID identity by positioning themselves as capable and independent, and barriers to independence are barriers to developing a positive sense of masculinity among men with ID. Accordingly, both papers emphasised the importance of supporting people with ID to have an active role in decision-making in their everyday lives and to make meaningful choices around support and activities. This is in line with research that has asked people with ID what they want from their lives (Haigh et al., 2013; Richards, 2018). However, findings of both papers 1 and 2 indicated that the lack of male support workers in ID services hinders opportunities to explore identity and impedes the ability to choose between staff members.

The empirical paper found that ID services prioritise practical support above emotional/social support. Consequently, a lack of 1:1/leisure time with service users translated into a lack of meaningful conversations to support the development of identity. This may explain the systematic review finding that people with ID lacked opportunities to talk to others about their self-identities and struggled to articulate their identities. Both papers emphasised that a proactive approach to providing opportunities for people with ID to talk about and develop their identities is needed.

Services should provide specialist training to ensure that support workers feel confident in initiating these conversations appropriately.

One notable area of divergence between the two papers was around gender normativity within ID services. The systematic review found that stereotypical gender narratives and heteronormative assumptions among staff shape support and reinforce gender stereotypes among service users. Activities provided by services are organised around "normal" masculinity and femininity and service users are automatically treated as though they identify with the gender they were assigned at birth. Conversely, participating services in the empirical paper aimed to provide activities to suit everyone rather than being directed at either gender. Support workers aimed to embrace service users' individuality rather than treating them differently based on their gender. It is possible that this discrepancy is related to a bias in the empirical study sample. Some support workers expressed a particular passion for the topic and therefore may have been more aware of and open to embracing "norm-breaking" gender identities compared to professionals in the systematic review. Furthermore, being aware of the empirical study aim to explore support around the development of gender identity, support workers may have been concerned about their work being judged, leading to social desirability bias. This is an important reminder of the specificity of the sample and the limited generalisability of the findings, which need to be understood in the context of participants' individual experiences.

Impact

This research has the potential to have an academic impact and 'real-world' implications at multiple levels. Paper 2 is the only study to explore issues around gender identity and support in this area from the perspectives of both support staff and

men with learning disabilities, and paper 1 is the first systematic review to examine how people with ID understand their gender, including cisgender identities. Consequently, this research offers a unique contribution to the academic knowledge base. Facilitators and barriers to support with gender identity development were highlighted by both papers, enabling practical suggestions for improving practice (see Appendix P) and conducting future research to advance the field. The academic impact of the papers can be maximised by publishing the research in high impact journals and presenting at conferences, but also seeking to disseminate the findings to the wider array of multidisciplinary professionals providing care for the ID population (see 'Dissemination' section below).

The project's potential 'real-world' implications are far-reaching, with a range of possible beneficiaries including people with ID and their families, ID services, multi-disciplinary professionals, local authority commissioners and policymakers, and wider society. The implications include changes in attitudes within ID services and wider society around the importance of supporting gender identity development for people with ID; increased understanding of the support needs of the ID population; and changes in ID service policy and practice around gender-related support, hopefully translating into changes in the allocation of resources and improved quality of life and health outcomes for people with ID. Nevertheless, although there is potential wide-reaching impact from the project, the limitations of the small and homogenous sample in paper 2 must be noted. For example, supporting gender identity development for men with ID from ethnically diverse backgrounds or men with more severe/profound cognitive impairment was not explored.

The findings of both papers may be of interest to service users and may help them to make sense of and manage the negative impact of stigma. Service users may be encouraged that support worker participants in paper 2 strove to embrace their individuality and promote their independence. Regarding the potential to change practice in ID services, the findings of both papers may motivate service managers to introduce and place more emphasis on reflective spaces for staff, to increase awareness of any limiting assumptions such as the focus on the ID identity to the exclusion of other identities. Service managers may also strive to shift the values of services, including a greater emphasis on fostering a sense of belonging and increased support with socialising. To achieve this, both papers indicate the need for specialist training for support staff, and the project findings could be used to inform such training.

It is recognised that a change in organisational policies and the resources of services is needed to enable this cultural shift in ID services. For service-level change to occur, policy must reflect the crucial role services play in supporting people to develop their identities. Appropriate funding must be invested in order that services can provide emotional/social support as well as practical support. Gender-blindness in policies also needs ameliorating, to close the policy-practice gap in terms of the Government's priority of the social inclusion of people with ID versus the reality of service and funding priorities. Considering the importance of promoting independence that was evidenced by both papers, local authorities may be motivated to commission more advocacy services. However, given the climate of austerity (Maynard, 2017; Roy, 2019), this outcome seems unlikely. Nevertheless, it is anticipated that structural-level change would not only offer benefits to the quality of life of people

with ID, but at a societal level would provide benefits in terms of cost savings for healthcare (The Kings Fund, 2010). Furthermore, at the societal level the findings of both papers aim to reduce stigma and promote progressive attitudes around the gender identity of the ID population.

The impact of any changes in policy and allocation of resources and funding would need to be formally evaluated to maintain structural-level changes, using both quantitative and qualitative longitudinal data (Pomeroy & Sanfilippo, 2015). Evidence-informed health policy is most successful if researchers share findings in an accessible way to facilitate policymaker understanding (Pomeroy & Sanfilippo, 2015). Therefore, when the project findings are disseminated to participating ID services, I can gain feedback on whether the key messages are clear and user-friendly. I can also evaluate the reaction of service managers to the findings and discuss the feasibility of implementing the recommendations, to understand any barriers. Over the longer-term, ID services could evaluate the impact of changes (such as increased reflective spaces for staff, increased support with socialising, and new staff training) using pre-post measures of service user wellbeing and anonymous satisfaction questionnaires with closed questions alongside qualitative feedback. Observational data could also be used, for example, monitoring the information about service user wellbeing that is communicated in staff handovers.

Dissemination

To date, the empirical study findings have been disseminated locally via virtual presentations to staff and students at Royal Holloway University of London. All participants and co-researchers have accepted the offer of a summary of the findings. The lay summary of the project will be disseminated to the participating ID

services. To maximise the impact of research it is necessary to use the most effective and relevant channels to communicate findings to the target audience (ESRC, 2021). Feedback from people accessing the Community Team for People with Learning Disabilities (East Surrey) indicates that videos are more accessible than easy-read materials and are preferred by service users. Consequently, I plan to create a short video of myself talking through the lay summary for service user participants. I will seek service user consultation on the language used in the easy read summary of the project that will form the basis of (and be provided alongside) the video. This video can also be advertised on the website of Surrey and Borders Partnership NHS Foundation Trust.

To disseminate the research to an academic audience, both papers will be prepared for publication and submitted to a number of journals in order of preference based on their impact ratings and aims/scope (SCImago, 2021). Additional considerations were whether the journals accept systematic reviews and/or are receptive to qualitative research. The potential journals identified for the empirical paper are: Advances in Mental Health and Intellectual Disabilities; Intellectual and Developmental Disabilities; the Journal of Intellectual Disabilities; and the British Journal of Learning Disabilities. The systematic review will be submitted to the Journal of Intellectual Disability Research; the Journal of Intellectual Disabilities; and the Tizard Learning Disability Review. An application will be made to the Division of Clinical Psychology Faculty for People with Intellectual Disabilities, to present the findings at the joint North and South Thames regional faculty meeting and/or a Special Interest Group meeting in the autumn. Additionally, we will apply to present a

poster at the Seattle Club Conference on Research in Intellectual and Developmental Disabilities in December 2021.

I will also seek to publicise the findings via Community Care, to target social care professionals. When contacting Community Care, I will tailor communication of the findings and emphasise the key recommendations for how services can improve care for people with ID, as this is likely to be of most interest to social workers and will maximise the likelihood of Community Care featuring the research. Additionally, I contacted the Supported Loving organisation to discuss the most beneficial way to disseminate the findings to their network. It was agreed that the findings will be presented at a network meeting or webinar during the summer.

Given the priority to promote the social inclusion of people with ID and increase their access to mainstream services, I feel it is important to raise awareness of these findings within a broader audience beyond the immediate ID field. To achieve this, I intend to approach the editors of the British Psychological Society's 'The Psychologist' magazine and request to disseminate the research within the broader clinical psychology profession. Given the growing interest in gender identity in the mass media (The Independent, 2021), it is possible that social media and other media outlets of interest to the general public could be used to promote the research. I intend to promote the link to the accessible video describing the study findings on Twitter and the Supported Loving Facebook page. When approaching different media outlets, I would emphasise the relevance of the findings for their target audience, to maximise the likelihood of them promoting the research. This would be in line with the broader aim of the project to advocate for the voices of people with ID to be heard within a wider audience and promote their access to valued "ordinary" lifestyles.

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Appendices

Appendix A: Search Terms for Systematic Literature Review

SEARCH CATEGORY	TERMS USED
INTELLECTUAL DISABILITY	"Learning disabilit*" OR "Intellectual disabilit*" OR "Developmental disabili*" OR "Developmental disord*" OR "Intellectual developmental disorder" OR "Learning disord*" OR "Pervasive developmental disord*" OR "Learning difficult*" OR "Mental handicap" OR "Mental retard*"
AND	
GENDER IDENTITY	"Gender development" OR "Gender identity" OR Identity OR "Gender role" OR "Gender identity development" OR "Development of gender" OR "Development of gender identity" OR "Development of gender role" OR "Sex role*" OR "Gender identity formation" OR "Gender disord*" OR "Gender identity disorder*" OR "Gender reassignment" OR "Cross-dress*" OR "Transvesti*" OR "Transsexual*" OR "Disorders of gender identity" OR "GID" OR "Gender dysphoria" OR "Transvestic fetishism" OR "Sex change" OR "Gender-related issues" OR "Gender-related difficulties" OR "Gender-related disorder" OR "Gender-based issues" OR "Gender-based difficulties" OR "Gendered" OR "Gender-

	neutral" OR "Gender relations" OR Cisgender OR Cismale OR Cisfemale OR Androgen* OR Androgynous OR "Neuter gender" OR "Genderfluid" OR "Third-gender" OR "Third gender" OR Agender OR Genderless OR "Gender-less" OR "Genderfree" OR "Gender-free" OR Genderplay OR Neutrois OR "Cross-gender" OR "Non-binary" OR "Gender nonconforming" OR Bigender OR Ambigender OR Trigender OR Pangender OR Genderqueer*

Appendix B: Quality Appraisal (Qualitative Studies)

Included papers	Clear statement of research aims?	Qualitative method appropriate ?	Research design appropriate ?	Recruitment strategy appropriate ?	Data collection appropriate ?	Relationship between researcher and participant discussed?	Ethical issues considered?	Rigorous data analysis?	Clear statement of findings?
Barron (2002)	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Unclear
Bjornsdottir (2017)	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
Bjornsdottir (2020)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
Brown (2010)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
Charnock (2013)	Yes	Yes	Yes	Unclear	Yes	No	Unclear	Unclear	Yes
Elderton (2014)	Unclear	Yes	Unclear	Yes	No	Unclear	Unclear	No	No
Fitzgerald (2013)	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes
Groves (2018)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Mutua (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Midjo (2018)	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes
O'Shea (2020)	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Unclear	No
Sommarö (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Included papers	Clear statement of research aims?	Qualitative method appropriate ?	Research design appropriate ?	Recruitment strategy appropriate ?	Data collection appropriate ?	Relationship between researcher and participant discussed?	Consideratio n of ethical issues?	Rigorous data analysis?	Clear statement of findings?
Tallentire (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Toft (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wheeler (2007)	Yes	Yes	Yes	Unclear	Yes	Yes	Unclear	Yes	Yes
Wilson (2011)	Yes	Yes	Unclear	Unclear	Yes	Unclear	Yes	Yes	Yes
Wilton (2020)	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes

Appendix C: Quality Appraisal (Quantitative and Mixed-Methods Studies)

Cross-sectional analytical studies

Included papers	Sample inclusion criteria clearly defined?	Participants and setting described in detail?	Exposure measured in valid and reliable way?	Objective criteria used for measurement of the condition?	Confounding factors identified?	Confounding factors dealt with?	Outcomes measured in valid and reliable way?	Appropriate statistical analysis used?
Burns (2011)	Yes	Yes	No	Unclear	Yes	Unclear	No	Unclear
Umb-Carlsson (2006)	Yes	Yes	Yes	Yes	No	Yes	No	Yes

Quasi-experimental studies

Included papers	Order of 'cause' and 'effect' variables clear?	Compared participants similar?	Compared participants receiving similar treatment/care, other than the exposure of interest?	Control group?	Multiple measurements of the outcome both pre and post the exposure?	Follow up complete? Or, differences between groups adequately described and analysed?	Outcomes included in any comparisons measured in the same way?	Outcomes measured in a reliable way?	Appropriate statistical analysis used?
Abelson (1978)	Yes	Unclear	Unclear	Yes	N/A	N/A	Yes	Unclear	Unclear
Kifune (1990)	Yes	Unclear	Unclear	No	N/A	N/A	Yes	Unclear	Unclear

Case series

Included paper	Clear inclusion criteria?	Condition measured in a standard, reliable way for all participants?	Valid methods used for identification of the condition?	Consecutive inclusion of participants?	Complete inclusion of participants?	Clear reporting of participant demographics?	Clear reporting of clinical information?	Outcomes or follow up results clearly reported?	Clear reporting of the setting information?	Statistical analysis appropriate?
Parkes (2009)	Unclear	Unclear	Unclear	No	Unclear	Yes	Yes	No	No	Yes

Mixed-methods study

Included paper	**SCREENING QUESTIONS**				
Bedard (2010)	**Clear research questions?**	**Data allow research question to be addressed?**			
	Yes	Yes			
	QUALITATIVE QUESTIONS				
	Qualitative approach appropriate?	**Data collection method adequate?**	**Method for data collection and analysis clear?**	**Interpretation of results sufficiently substantiated by data?**	**Stages of research process coherent? (Including influence of the researcher)**
	Yes	No	No	No	No
	QUANTITATIVE (DESCRIPTIVE) QUESTIONS				
	Sampling strategy appropriate?	**Sample representative?**	**Measurements appropriate?**	**Risk of non-response bias low?**	**Statistical analysis appropriate?**
	No	No	No	Unclear	Yes
	MIXED METHODS QUESTIONS				
	Adequate rationale for mixed-methods design?	**Components of study effectively integrated?**	**Output of integration of qual and quant components adequately interpreted?**	**Inconsistencies between qual and quant results adequately addressed?**	**Both components adhere to appropriate quality criteria?**
	Yes	No	No	No	No

Appendix D: Themes and Subthemes with Contributing Papers

Theme	**Understanding of self-identity**		**Barriers to understanding/developing gender identity**				**Recommendations for practice**	
Subtheme	Understanding of gender identity	Sexual identity	Barriers to autonomy	Lack of opportunity to explore identity	Competing identities	Gender normativity	Opportunities to develop identity	Promoting autonomy
Barron (2002)	✓	✓	✓	✓	✓	✓		
Bjornsdottir (2017)	✓	✓	✓	✓	✓	✓	✓	✓
Bjornsdottir (2020)		✓	✓	✓		✓		✓
Brown (2010)					✓	✓		✓
Charnock (2013)	✓			✓	✓		✓	✓
Elderton (2014)							✓	
Fitzgerald (2013)		✓	✓	✓	✓	✓		✓
Groves (2018)	✓		✓	✓	✓	✓		✓
Mutua (2015)	✓		✓	✓	✓	✓	✓	✓
Midjo (2018)	✓	✓	✓	✓	✓	✓		✓
O'Shea (2020)		✓	✓	✓	✓	✓	✓	✓
Sommarö (2020)			✓					
Tallentire (2020)			✓				✓	
Toft (2019)			✓	✓	✓	✓	✓	

Theme	**Understanding of self-identity**		**Barriers to understanding/developing gender identity**				**Recommendations for practice**	
Subtheme	Understanding of gender identity	Sexual identity	Barriers to autonomy	Lack of opportunity to explore identity	Competing identities	Gender normativity	Opportunities to develop identity	Promoting autonomy
Wheeler (2007)	✓	✓	✓	✓	✓	✓	✓	✓
Wilson (2011)	✓		✓	✓				
Wilton (2020)	✓	✓	✓	✓	✓	✓	✓	✓

Appendix E: Email Confirming Royal Holloway University of London Ethical Approval

Ethics Application System <ethics@rhul.ac.uk>
Fri 03/07/2020 11:10
To: Ireland, Katherine (2018)
From: ethics@rhul.ac.uk

Project title: Embracing gender identity in men with intellectual disabilities

REC ProjectID: 2059

Your application has been approved by the Research Ethics Committee.
Please report any subsequent changes that affect the ethics of the project to the University Research Ethics Committee ethics@rhul.ac.uk

Appendix F: Information Sheet (Easy Read)

Department of Psychology, Royal Holloway, University of London
Egham Hill, Egham TW20 0EX

Web: https://www.royalholloway.ac.uk

'What Being a Man Means to Me'
PROJECT INFORMATION SHEET

What is this information sheet for?

This sheet tells you about this project. It will help you choose if you want to take part or not.

Who is doing this project?

My name is Katie Ireland. I am a Trainee Clinical Psychologist. I am doing this project with Royal Holloway University.

What is this study about?

We are interested in what it is like being a 'man' for young men with learning disabilities.

What will the interview questions be about?

	We would like to ask you questions about: • What being a ‘man’, or a ‘woman’ means • How you feel about being a man • How your support worker helps you to feel like a ‘man’ We are interested in **your** experiences. We hope this project may help make services better for men with learning disabilities in the future.
	**Who can take part in the research?** • Men with a learning disability • Aged 18 – 35 years old • Who can understand what it means to take part in the project

	**What will happen if I take part in the project?** You will meet with a researcher to talk about the project. You will sign a consent form to say that you are happy to take part. You will meet with the researchers for an interview. This will take about 1 hour. The interview will be in a private room at the service that supports you.
	We will use a tape recorder to record what you say.
	We will talk to your key worker or a support worker who knows you well. We will ask them questions about: • Their experience of supporting you as a ‘man’

<table>
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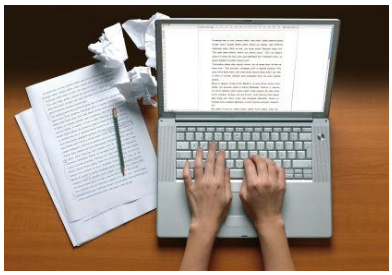
	details are at the end of this information sheet.
	**What will happen at the end of the project?** We will write a report about the project, to let people know what we find out. The report will be about what everyone who took part said. We will write an easy read summary of the project. This might include some of the things that people said, but **not** people's names. We will write about the project in a way that no one will know that you took part.
 	**Is the research private?** Yes. We will only share information if we are very worried about you or someone else's safety. Only if we need to, we may share information with someone who can help to keep you safe, like your GP or the Learning Disability

	Team. We will let you know if we need to do this.

	**Do I have to take part in the project?** No, It's your choice… You do not have to take part in the interview. You choose what you want to say. You can stop the interview at any time. It is ok to change your mind. If you decide to take part in the interview or not, it will not change the way services work with you.

	There might be good things and bad things about being interviewed.

It might be good to talk to someone about things you don't normally talk about.

We hope that this project will help other men with learning disabilities to get the support they need around how they feel about being a man.

We will offer you £10 payment for your time.

But talking about how you feel about being a man might be hard or embarrassing.

You do not have to answer any questions you do not want to. We will ask you how you feel after the interview and give you some information that might help.

The University have checked how this research is being done. They have agreed that the research is being done safely.

	**How have service users helped us to develop this study?** A man with a learning disability helped us to make the study information sheets and interview questions easy to understand.
	**Can I talk to someone about the project?** Yes. You can talk to your psychologist, family, friends, carer, or GP if you have any questions or want advice.
 	You can talk to Kate Theodore / Karen Dodd (research supervisors) if you are unhappy with anything about the research.
	If you have questions about the project you can call and leave a message for Katie Ireland or Kate Theodore, the researchers. Katie's telephone number is: 01784 414 012

	Kate's telephone number is: 01784 414 303 Katie or Kate will call you back.
	You can email Katie or Kate. Katie's email address is: Katherine.ireland.2018@live.rhul.ac.uk Kate's email address is: Kate.theodore.2018@rhul.ac.uk
	**THANK YOU FOR YOUR TIME** **Please tick here if you want to find out more about taking part in the research** ☐ ☐ I agree that Katie Ireland (the researcher) can arrange a meeting with me to explain the project and answer my questions.

Appendix F: Information Sheet (Support Worker Version)

Department of Psychology, Royal Holloway, University of London
Egham Hill, Egham TW20 0EX

Web: https://www.royalholloway.ac.uk/

Gender Identity Project
INFORMATION SHEET
Support Workers

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve. If you agree, one of our team will meet with you to go through the information sheet with you and answer your questions. This should take about 10 minutes.

What is the project about?

Staff working with people with learning disabilities are largely female, which may lead to issues in supporting men with LD to explore and develop their masculinity.

This project is about the development of **gender identity in men with LD**. We are aiming to find out about issues related to gender and masculinity and how men with LD are supported in this area. We will be asking men with LD questions about their experience of being a man (or other gender), and how they have been supported to understand and express their gender.

We would also like to hear about these things from **people that know them well**. This could be their Key Worker or a Support Worker who knows them well and supports them frequently. We are interested your experiences of supporting them.

Why me?

Someone in the learning disabilities team thought that the man that you support may be able to take part in this project. As their Key worker or Support worker, we'd like to hear from you as well.

Do I have to take part?

It is up to you to decide whether to join the study. If you like, you can talk to others about the study before you decide. If you agree to take part, you can change your mind at any time.

What will happen if I take part?

A researcher will arrange to meet with you at the learning disabilities service where you work and will answer any questions you have about this study information sheet. You will then be asked to sign a consent form, to confirm that you are happy

to participate in the study. You will be given a copy of the consent form and participant information materials to take away with you. **An interview will then be arranged, which will last for around an hour**. You can choose how much to say. We will use a **tape recorder** to record what you tell us.

We will invite some participants to give feedback on the themes we identify from the interviews. This is to check that you feel that the themes accurately describe your experience. This aspect of participation in the project is optional.

After we have talked to 4-6 young men and their support workers, we will write a report. Participants will not be identifiable from the report. We will share the results with the service. If you are interested in hearing about the results, you can also have a copy of the summary of the results.

Will my information stay confidential?

The interview with you will be separate from the interview with the man you support. You won't know what each other said. We will let people know what was said in the interviews, but not who said it. That means we won't use your name.

What are the pros and cons of taking part?

We think it is important to give you all the information you need to make up your mind, so we have listed possible disadvantages and advantages of taking part.

Possible disadvantages:	Possible advantages:
-Taking up your time.	-An opportunity to be heard, in a way that is important and useful.
-Discussing sensitive and private topics, such as the development of gender identity.	-An opportunity to reflect on topics, like gender identity, which can be difficult to talk about with other people.
	-An opportunity to reflect on issues in supporting the man with LD.
	-An opportunity to feedback concerns, comments or requests to the clinical team, which may kick-start change.
	-An opportunity to contribute to research which may influence future services for men with LD.
	-We will provide information and resources after interviews that we hope can help you to talk about gender identity with the man you support.

-The man you support will be offered £10 for their participation.

What will happen if I don't want to carry on with the study?

You can change your mind and decide not to take part in the study at any point, without giving a reason, until we have completed the study. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible. You can find out more about how we use your information by contacting the study coordinators (please see the end of this Information Sheet for contact details).

What if there is a problem?

If you have a concern about this study, you should speak to the research team who will do their best to answer your questions [01784 414 012]. You can talk to Dr Kate Theodore / Dr Karen Dodd (research supervisors) if you are unhappy with anything about the research.

How will my information be kept confidential?

Your information will be stored securely. Your interview answers will be stored without your name on them. The research team will replace your name with a code number or pseudonym. Audio recordings will be deleted as soon as the interview has been typed up. Your personal details, such as name and address, will be destroyed once we have met with you to feed back the results. Your consent form will be kept for 2 years, and your interview answers will be kept for 5 years then destroyed. Only the researchers and people who inspect researchers will have access to your data. These people will not be able to identify you from the information. Other researchers will not be able to contact you about future research.

Will the use of my data meet GDPR rules?

GDPR stands for the General Data Protection Regulation. In the UK we follow the GDPR rules and have a law called the Data Protection Act. All research using patient data must follow UK laws and rules. A Research Ethics Committee has checked that our project is designed in a way that protects the privacy of the people who take part.

What will happen to the results?

We will write a research paper about what we find, which may be published. Your name will not be in this. The paper will be written in a way that no one can work out that you took part in the project. All direct quotes that are included in the report will be anonymised.

Who is organising and funding the research?

Royal Holloway, University of London.

How have the public been involved in this study?

A service user was involved in the design of our project, by reviewing our study materials (such as the participant information sheet, consent form and interview questions) to check that they are accessible to service users with LD. We will also ask the service user to review the lay summary of our study findings.

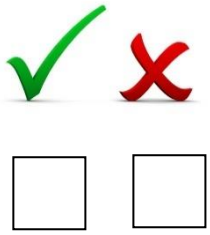
Who has reviewed the study?

Research projects are looked at by independent group of people, called a Research Ethics Committee, to protect people who take part. This study has been reviewed and given favourable opinion by the Royal Holloway, University of London Research Ethics Committee.

If you decide to take part, you will be given a copy of this information sheet and a signed consent form to keep.

THANK YOU FOR YOUR TIME

I give consent for a member of the research team to give my contact details to the research team, so that they can arrange a meeting to explain the research study, go through this information sheet, and answer questions.



If you want to find out more, please ask:

Royal Holloway
University of London
Egham Hill
Egham
TW20 0EX

Telephone:
01784 414 012

Katie Ireland
Trainee Clinical Psychologist

Kate Theodore
Senior Lecturer/
Clinical Psychologist

Appendix G: Consent Form (Easy Read)

Department of Psychology, Royal Holloway, University of London
Egham Hill, Egham TW20 0EX

Web: https://www.royalholloway.ac.uk

'What Being a Man Means to Me'

PROJECT CONSENT FORM

Department of Psychology, Royal Holloway, University of London
Egham Hill, Egham TW20 0EX

Web: https://www.royalholloway.ac.uk/

'What Being a Man Means to Me'
PROJECT INFORMATION SHEET

What is this information sheet for?

This sheet tells you about this project. It will help you choose if you want to take part or not.

Who is doing this project?

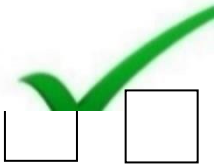
My name is Katie Ireland. I am a Trainee Clinical Psychologist. I am doing this project with Royal Holloway University.

What is this study about?

We are interested in what it is like being a 'man' for young men with learning disabilities.

	I have seen the Information Sheet	☐ ☐
	I understand what it says	☐ ☐
	I understand my information will be kept: • Confidential • In a safe place • and it will not have my name on it	☐ ☐

	I agree to take part in the interview	✓ ☐ ✗ ☐
	I agree for my support worker to take part in a separate interview. I understand we won't be interviewed together.	✓ ☐ ✗ ☐
	I agree to be tape recorded	✓ ☐ ✗ ☐

	I understand I can change my mind at any time	

.....	.....	.....
Name of Participant	Date	Signature

.....	.....	.....
Name of Person taking Consent	Date	Signature

Appendix G: Consent Form (Support Worker Version)

Department of Psychology, Royal Holloway, University of London
Egham Hill, Egham TW20 0EX

Web: https://www.royalholloway.ac.uk/

Gender Identity Project

CONSENT FORM
Support Workers

Name of Researcher: Katie Ireland

I confirm that I have read and understand the information sheet (dated X, version X) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

I understand that relevant data collected during the study may be looked at by individuals from regulatory authorities, where it is relevant to my taking part in this research.
I give permission for these individuals to have access to these data. ☐

I agree to take part in the above study. ☐

I agree that the interview can be tape recorded. ☐

…….	…….	…….
Name of Participant	Date	Signature
…….	…….	…….
Name of Person taking Consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file

Appendix H: Demographics Form (Easy Read)

About Me:

You can choose how much information you give to these questions. You can choose not to answer any questions you don't want to.

Gender: (man / woman / transgender / don't want to say)

_____

How old are you?

_____ **years**

What is your ethnic group?

_____

White: British Irish Other

Black: Caribbean African Other

Asian: Indian Pakistani Bangladeshi
Other Asian Background

Mixed: White/Black Caribbean
White/Black African
White/Asian
Other Mixed Background

Chinese Other ethnic group

What is your religion?

_____
_

What sort of place do you live in? Do you live by yourself / with other people / in supported living? Anything else about where you live that is important?

_____

_____

How many people do you live with? _____

How many are men? _____

How many are women? _____

Is your key worker a man or a woman? _____

Appendix H: Demographics Form (Support Worker Version)

Gender Identity Project

Participant information:

You can choose how much information you give to these questions. You can choose not to answer any questions you don't want to.

How long have you been working with people with learning disabilities for? (in months/years)

_____

How long have you been supporting the service user for? (in months/years)

_____

How much support do you provide to the service user? (i.e. number of hours of support per week and frequency of support sessions)

_____

What is your gender: (man / woman / transgender / don't want to say)

_____

To your knowledge, what gender does the service user your support identify as?
(man / woman / transgender / don't want to say)

_____

How old are you?

_____ **years**

What is your religion?

What is your ethnicity?

_____

White: British Irish Other

Black: Caribbean African Other

Asian: Indian Pakistani Bangladeshi
Other Asian Background

Mixed: White/Black Caribbean
White/Black African
White/Asian
Other Mixed Background

Chinese Other ethnic group

What sort of place does the service user you support live in? Do they live by themselves / with other people / in supported living? Anything else about where they live that is important?

_____

_____

If they live with other service users, please provide information about the gender mix of the home (i.e. the number of male service users and number of female service users):

_____

Appendix I: Interview Schedule (Service Users)

Introduction

- Thank you very much for coming to speak to me today.
- Do you have any questions about anything at all on the information sheet?
- It's important to let you know that these questions are in no way testing you or your relationship with your support worker, they are simply to find out about your life experiences. There are no right or wrong answers, I just want to hear lots about your life and what you think about things.
- How are you feeling about talking to me today? Do you have any worries about talking with me today?
- Is there anything I can do to make it feel more comfortable or reassure you?
- If you want to stop the interview or take a break at any time, please let me know and we can do that.
- How will I know if you are feeling uncomfortable or want to stop or take a break? Will you be able to tell me, or give me some other sort of sign?
- I'm going to take my time with the interview and will be looking at my questions to think about the best way to ask them. *[hold up sheet of paper to let participant know I will sometimes look away from computer screen]*
- I will offer you a break whenever I need to pause and check that I have asked all of my questions.

Confidentiality

As explained on the information sheet, everything that we talk about today will be kept private. The only reason I would need to tell anyone else about anything that we talk about is

if you told me that you, or someone else might be harmed. If that did happen, I would talk to you about it before talking to anyone else. Do you have any questions?

Are you ok to start the interview?

Interview

Own Identity / getting to know the participant

- I don't know you very well yet, so could we talk about the photo of yourself that you have chosen? What does this photo show about you? Why did you choose this photo?
- Ask follow-up questions to gain more detail about any interests identified in the photo. **Ask for each interest separately: "What do you like about [cycling]?" "Who do you go with?"**

  [NB: Participants will be contacted in advance and asked to select a photo of themselves, if they would like to]
- I want to find out more about you… Can you tell me a bit about yourself?
- What things are important to you?

  Activities (an area where gender identity can be expressed):

- Can you tell me about what you normally do in the day?
- What do you like doing? [For example, what sports/music/TV shows do you like?]
- What don't you like doing?
- **For each activity participant likes/does:** You said you like [activity]. Do you think this feels like a 'manly' activity or a 'womanly' activity or something different? Why do you say that / tell me more… **ASK "DO YOU LIKE TO USE THE WORDS "MAN" AND "WOMAN", OR "BOY" AND "GIRL"?**

Possible prompts:

- Do you think there is a difference between manly activities and womanly activities?
- What kind of activities do you think men like doing?
- What kind of activities do you think women like doing?

[If needed, provide visual prompts of typically masculine/feminine activities and alternative activities that seem typically gender-neutral]

- Do you think people from different countries like to do different activities for fun?
- Do you think there is anything that you like doing because of where you are from?
- Do you think people from different religions like to do different activities for fun?
- Are you religious? Do you think there are any activities you like doing because of your religion?

Clothing (an area where gender identity can be expressed):

- What do you normally like to wear?

[If needed, provide visual prompts of typically masculine/feminine clothes and alternative clothes that seem typically gender-neutral]

- What type of clothes do you think are typically for men or typically for women?
- Do you feel that you dress in a manly/womanly way? Why/why not?
- Do you talk to anyone about things like what men should wear?

Possible prompts:

- Are clothes/fashion important to you? Why/why not?

OFFER BREAK

Support

- Tell me about your relationship with [support worker being interviewed]?
- What sort of things do you do together?

Possible prompts:

- How do you get on?
- What is good about time with/support from [support worker]?
- How do you work together?
- Are there things that you like about how you work together?
- Are there things that are difficult about how you work together? Tell me more about that.

- Who suggests the activities you do? Who chooses the activities?
- Do you think that the suggested activities are suitable for a man? / Do those activities make you feel manly?
- Would you like to do different things with [support worker]?
- What sort of places do you like to go to?
- What sort of places would you like to go to in the future?
- Who decides the places you go to?
- Do you think that the places are suitable for a man? / Do those places make you feel manly?
- Is there anyone else [specify not support worker being interviewed] who you are close to who does activities with you? Who?
- Do you do different things with them than with [support worker]? Why/why not?
- What type of activities do they suggest? Do they help you to feel like a man?
- Are different activities suggested when you are supported by a man or a woman? How do you feel about that?
- Would you prefer to be supported by a man or a woman when you do [activities participant enjoys]? Why?

OFFER BREAK

Identity as a man / woman

- I am going to ask you some questions about what it means to be a man now…
- **I know that I am a woman, and that might make some of the questions difficult to answer in front of me. But I am really interested in what you think. You will not offend me. There are no right or wrong answers. I want to know your honest answers.**

- What do *you* think it means to be a man? [or a woman, if participant identifies as a woman]

Possible prompts:

- Do you think men and women are different? Tell me more about why you say that? How are they different? How are they the same?
- How do you think life is different for a man compared to a woman?

- Would you say you are a man or a woman or would you say something else (like…. Examples…?)? Tell me more about why you say that…? **CAN SHOW TRANSGENDER BOOKLET PAGES 1-4 IF NEEDED**
- Can you tell me what being a man (or other gender) is like for you?

Possible prompts:

- When you were growing up, what kind of things told you that you are a man and not a woman?
- Is being a man/other gender something that's important to you? Why/why not?

- What do *you* like about being a man?
- Is anything good about being a man (or other gender the person identifies as)?
- Why might a man be happy that he is a man?
- What do you think might be good about being a woman?
- Why might a woman be happy that she is a woman?
- **Ask the participant afterwards if they would have answered differently if a man had asked them that question.**
- **Ask if they felt in any way awkward/uncomfortable being asked that question by a female.**
- Do you think people treat you differently to how they would treat a [opposite gender] man/ woman? Can you tell me more about that?

Possible prompts re sexuality/relationships, depending on what the participant raises:

- What do you think about having a girlfriend or a boyfriend?
- Have you had a girlfriend/boyfriend in the past?
- Would you like to have a girlfriend/boyfriend? Why/why not?

WHAT DOES THE WORD "CULTURE" MEAN TO YOU?

Explain if needed: Sometimes if people are from the same place, they might have a similar way of living or share some traditions, like celebrating Christmas, or if you are from India you might like eating Indian food like curries. Can you think of any examples? Would you like me to show you any more examples? **Show visual prompts if needed.** People from the same place might eat certain types of food or wear certain types of clothes. They might speak the same language or have the same religion.

- Are there are any things that you like doing because of your culture specifically?
- Do you think that your culture/ethnicity/religion influences how you show that you are a man?

OFFER BREAK

Support with the development of gender identity

Now I will ask some questions about the support you receive from [support worker]…

- What sort of thing does [support worker] help you with?
- Do they support you with manly things?
- How has your support worker supported you with specifically being a man?

Possible prompt:

- Do they help you with private things? Like washing?
- Do you and [support worker] chat a lot? What sort of thing do you talk about?
- Do you talk about manly things? Do you talk about being a man?
- If yes: What is that like? Is it easy or difficult?
- If no: Do you think you could talk to your support worker about being a man [or other gender] if you wanted to? Why / why not? Tell me more about that…

Possible prompts:

- Are there things you do together that you think help you feel like a man specifically / help you to feel manly?
- Are there things you do together that you think make it difficult to feel like a man?
- Do you do any things together that feel girly / that make you feel like a woman?

- Would you like your support to be different? How/why?
- Would you like more support with being a man?
- Would you prefer to have that support from a man or a woman? Why?

Possible prompts:

- Do you have support at home with personal care / household chores? Would you prefer to have this support from a man or a woman? Why?

- Do you prefer chatting to a man or a woman support worker? Why?
- Would you prefer to talk to a man or a woman support worker about private things? … Like sex and relationships? Why?

- Do you think it's different working with a man support worker than a woman support worker? Why/why not?
- Do you change how you act when you are supported by a man compared to a woman?
- What makes you do that? How do you change / What are the changes you make?

Ending

- What's it been like talking to me today?

Possible prompts:

- Has anything been hard? Has anything been nice?
- Has anything made you feel sad? Has anything made you feel happy?
- Has anything been confusing to understand? *[If yes, re-phrase and re-ask question]*
- Is there anything that we have not talked about that you think is important or that you would like to tell me about?

Debrief

What will happen next – Thank you very much for talking with me today. I will be talking to your support worker and other people and their support workers and asking them similar questions. I will listen to each interview and write up what people say. After I've done that, each recording will be deleted. The written script will not have your name on it. I will look at all of the written interviews, looking for themes and links. This is called 'analysis'. Then I will write up the findings up into a report for my University. I would also like to publish the findings so that more people can hear about what is important to people with learning disabilities about being a man. I will come back to the service to talk about my findings.

- Do you have any questions about anything that we have talked about or the study in general?
- When I've looked at what everyone has said, I would like to come back and find out if the people interviewed think my findings fit with their life experience. Would you like me to contact you so that you can give your feedback on what I find?
- If so, what is the best way to get in touch with you about this? By phone / email / contact with your support worker first?
- When the study is finished, I would like to tell everyone I spoke to what I found. Would you like to hear about what I found?
- If so, what is the best way to get in touch with you about this? By phone / email / contact with your support worker first?

Appendix I: Interview Schedule (Support Workers)

Introduction

- Thank you very much for coming to speak to me today.
- Do you have any questions about anything at all on the information sheet?
- It's important to let you know that these questions are in no way a judgement or evaluation of your work, they are simply to find out about your experience of supporting men with ID to understand and express their gender identity.
- How are you feeling about talking to me today? Do you have any concerns about talking with me today?
- Is there anything I can do to make it feel more comfortable or reassure you?
- If you want to stop the interview at any time, please let me know.
- If you want to take a break for any reason at any point, please let me know and we can do that.
- I will be looking at my interview questions to check I have asked everything I want to ask from time to time.

Confidentiality

As explained in the information sheet, everything that we discuss today will be treated confidentially. The only reason I would need to involve anyone else in our discussion today or tell anyone else anything that we talk about is if you told me that you, or someone else were at risk of harm. If that did happen, I would discuss it with you before talking to anyone else. Do you have any questions? Are you ok to start the interview?

Interview

Service user's identity

- How would you describe [service user]?

- How do you think [service user] would describe himself?

Possible prompts:

- Can you give me an example of that?

Potential areas where gender identity can be explored/expressed

Activities:

- Can you tell me about what [service user] normally does in the day?

Possible prompts:

- What does [service user] like doing? [For example, what sports/music/TV shows does he like?]
- What doesn't he like doing?
- Do you think that [service user's] culture/ethnicity/religion influences the type of activities they like to do?
- What sort of places does [service user] like going to? / Where would [service user] like to go? Why?
- Who suggests/chooses the activities [service user] does? / Who decides the places [service user] goes to?
- Do you think that the suggested activities/places are suitable for a man?
- Are different activities suggested when [service user] is supported by a male or female support worker? How do you feel about that? How do you think [service user] feels about that?
- Do you notice that [service user] changes their behaviour when they are supported by a man compared to a woman? Can you give me some examples?

- Is there anyone else who is close to [service user] who supports them to express their gender? How do they do this?

  Clothing:

- What does [service user] normally like to wear?
- Do you feel that he dresses in a masculine/feminine way? Why/why not?

Possible prompts:

- Do you think that clothes/fashion are important to [service user]? Why/why not?

Service user's gender identity

- How do you understand the term 'gender identity'?
- ***For the purpose of this study, gender identity will be defined as a sense of oneself as being a woman or man. This sense is separate from our biological sex and social roles. Agree with support worker how they would prefer to refer to it throughout the interview, e.g. 'develop gender identity' or 'become a man']***
- Do you think [service user] identifies as a man/woman/other gender? What has led you to this conclusion? Can you give me an example?

Possible prompts:

- Do you think that being a man is important to [service user]?
- What do you think [service user's] understanding of gender identity is?
- What do you think the experience of becoming a man/other gender has been like for [service user]? Can you give me an example?

- Do you think that [service user's] culture/ethnicity/religion influences how they express their gender?

Supporting service user to develop their gender identity

- What is supporting [service user] to become a man like? Can you give an example?
- How have you tried to help [service user] to understand/develop/express their gender identity?

Possible prompts:

– Can you give me an example of something that has been difficult when supporting [service user] to become a man?
– What has been easy?
- Do you think that having learning disabilities has affected the way that you see [service user] as a man/woman?
- Do you think that having learning disabilities has affected the way that other people see [service user] as a man/woman?
- What impact (if any) has [service user] having learning disabilities had on the process of supporting him to become a man? Can you give me an example of that?

- What do you think could be improved about the support [service user] has received around becoming a man? Can you give me an example?

Sexuality:

- What do you understand [service user's] sexuality to be? How have you reached this conclusion? Have you discussed this with them?

Possible prompts:

- Can you tell me about [service user's] experience of girlfriend/boyfriend relationships?

- Do you believe that [service user] would like to have a girlfriend/boyfriend? Why/why not?

Ending

- What's it been like talking to me today?

Possible prompts:

- Has anything been hard? Has anything been good to talk about?
- Has anything made you feel sad? Has anything made you feel happy?
- Has anything been confusing to understand? *[If yes, re-phrase and re-ask question]*
- Is there anything that we have not covered that you think is important or that you would like to tell me about?

Debrief

What will happen next – Thank you very much for taking part in the study. I will be talking to a number of other people and asking them similar questions. I will listen to each interview and write an interview script. After I've done that, each recording will be deleted. The written script will not have your name on it. I will analyse all of the written interviews, looking for themes and links. Then I will write them up into a thesis for submission to my University. I also aim to publish the study. I will come back to the service to talk about my findings.

- Do you have any questions about anything that we have talked about or the study in general?
- Would you like to receive information about the study findings directly? How would you like to receive this?
- When I have started to analyse some of the interview data, I would like to find out what the people interviewed think about the themes I am finding, to see if this fits

with their experience. Would you like me to contact you to invite you to give feedback on what I find?

Appendix J: Example of Coded Transcript

More interpretative coding /emerging themes:			Initial noting:
Young man with ID perceived as child-like Separating ID identity from identity as an adult man / ID identity detracting from identity as a man Pride in appearance	I:	So, I was hoping to start by asking you how you would describe Luke?	Focuses on appearance first rather than character. Repetition of the word "chap". Fondness. Influence of Luke's disability on his appearance. Comparison to a child. But "chap" seems more associated with an adult than child? And "looks good for his age" = also something one would say about an adult.
	R:	Oh! [*sounds surprised and bemused*] Erm… I would probably… physically I would describe him erm as I guess being quite kind of underdeveloped in terms – he's quite a short chap. Like kind of, you know, *almost* I guess kind of, quite child-like actually – in his stature. I know, you know, Downs, kind of limb-wise are always kind of a bit shorter anyway, erm [*pauses*] and, yeah quite a good-looking chap as well – looks good for his age, erm, looks after himself, likes kind of dressing quite well and smelling quite nice and	
	I:	Smelling quite nice! Aw, is that his interest, or his doing, is it?	
	R:	I think so yeah!	
	I:	Aw brilliant.	
	R:	I'm sure we might get on to – we might kind of explore what that's about in terms of his masculinity.	
	I:	Mmm definitely.	
Sense that service user is caring/empathetic and values connecting with people Sense of familiarity and understanding in their relationship	R:	Erm, and then kind of personal, I guess kind of personal traits that make Luke who he is, erm, he's a very caring person, very interested in kind of erm learning about you and what you do – he's always asking questions, which is really nice. Very funny – he's got a real kind of, quite *sharp,* and quite a blue sense of humour, which I think kind of, I dunno, we always seem to attribute people with LD as being not kind of switched on and not, you know, quick, but he's *super* switched on. He's good at kind of processing information and kind of, I get the impression that kind of societally, in terms of constructs around how society works I think he grasps that really well. But whether he can articulate that, and I think that's the other side of it, erm… he's quite forthcoming with questions but anything that's kind of bounced back or reflected back in a way, to explore, he maybe kind of struggles seeing that in his frame of reference. But again, that's just kind of part of his LD, erm… But yeah, he's a really infectious person to be around. Everyone that meets him loves him, and we have this thing when we go through Town and stuff – because I've worked over here for about twelve years, and all my work has been kind of Art and community development so I do know a lot of people in Town and stuff, and is quite a small Town really, when you start kind of piecing things together and third sector stuff – so we	Emphasising that his LD does not hold him back in terms of being sharp and switched on. Luke's quick sense of humour separating him from stereotypical views about people with LD. Grasping and processing information is a strength. Starts with his strengths then acknowledges communication more of an issue for Luke. "I think that's the other side of it" – referring to Luke's LD? Refers to his LD "again" – Luke's LD intertwined with his identity. Eager to learn but LD impedes this/hinders reciprocal conversation at times? "erm…" after talking about the impact of Luke's LD. More comfortable talking about his strengths than limitations perhaps? Well-loved/popular. "Infectious" – fun/funny
Awareness of limitations associated with ID / Difficulty acknowledging the impact of limitations (physical/cognitive). Sense that ID identity can dominate despite not wanting it to. Sense of enjoyment around connecting with others			

Sense that there can be a barrier for Luke re connecting with others (or that a barrier is expected but Luke manages this well)

Sense that Luke is caring /empathetic

Likes to be part of a group/belong to something

Separating self from "lad" culture

Sense of belonging to a group gives meaning to life

Caring/empathetic/loving

Service user is passionate about sport/being active

Importance of meeting people/ socialising

The impact of the pandemic on the service user's activities

Support with making connections

have this running tally of kind of who we know and who we bump into in Town and stuff, and he's always *miles* ahead so… And again he'll always stop and chat to people and he waves at cars if he sees people and I love the way he kind of takes people aback and they're like "Oh! Oh! Hi! You alright?!" It's really nice how he breaks down that barrier so well. And it's especially noticeable now I think as well, because I think we all need to be a bit more, kind of, *kind* and be chatting more to strangers and stuff, and he's great at that so… Yeah he's a really kind of humbling person to be around.

I: That's so lovely… that's really lovely. And how do you think Luke would describe himself?

R: Right, erm, funny, outgoing, active, erm… I think as well he likes this kind of, feeling part of a – you know, he likes this kind of being one of the lads kind of thing. Even though I'm not like "lad lad" *at* all, far from it, but, you know the stuff with [local rugby club] and things like that, erm he likes that association with different groups, and being part of something he really cares about and is really important, and is probably something he feels erm gives him a bit of kind of meaning in life I think, you know, and that goes for family as well – he's super close to family and things like that. But I think he would – I don't know whether he would use the word 'attentive' – but I think that he would, in that sense he would feel that he's quite attentive towards people's needs and erm a very loving person as well.

I: Mmm I got that sense too. [*pauses*] And, can you tell me a bit about what Luke normally does in the day?

R: Erm, so before lockdown he was doing loads of stuff with [local rugby club], because he volunteers quite a lot – a lot of it is kind of around active and sports-based stuff, erm, but day to day at the minute he's not doing a lot really. He's always got kind of care around or in the vicinity, so he's in supported living, he has a social worker, he does see his sister and brother and family quite a lot during the week as well for kind of food, *and* he also has - he goes and sees another… he stays with a couple – I don't think he stays over anymore but he goes and sees them, so he's with them on a Friday as well, so.

I: Ahh, and how does he know the couple?

R: That's also through the [support service].

Sense of fun and banter.

Friendly and confident. Surprises people. "Barrier" in terms of people keeping themselves to themselves/being unfriendly to strangers?

"Humbling" – because Luke highlights how we should all be treating each other? Or because he is friendly and confident despite the "barrier" of LD?

Repetition of the word "lad". Robert distinguishes himself from the rugby lads. Sense of not wanting to be associated with lad culture/vulgar banter?

Being part of a group gives meaning to life for Luke. Being part of something is really important.

Sense that Luke's ability to understand is greater than his ability to convey his understanding.

Empathic/loving person.

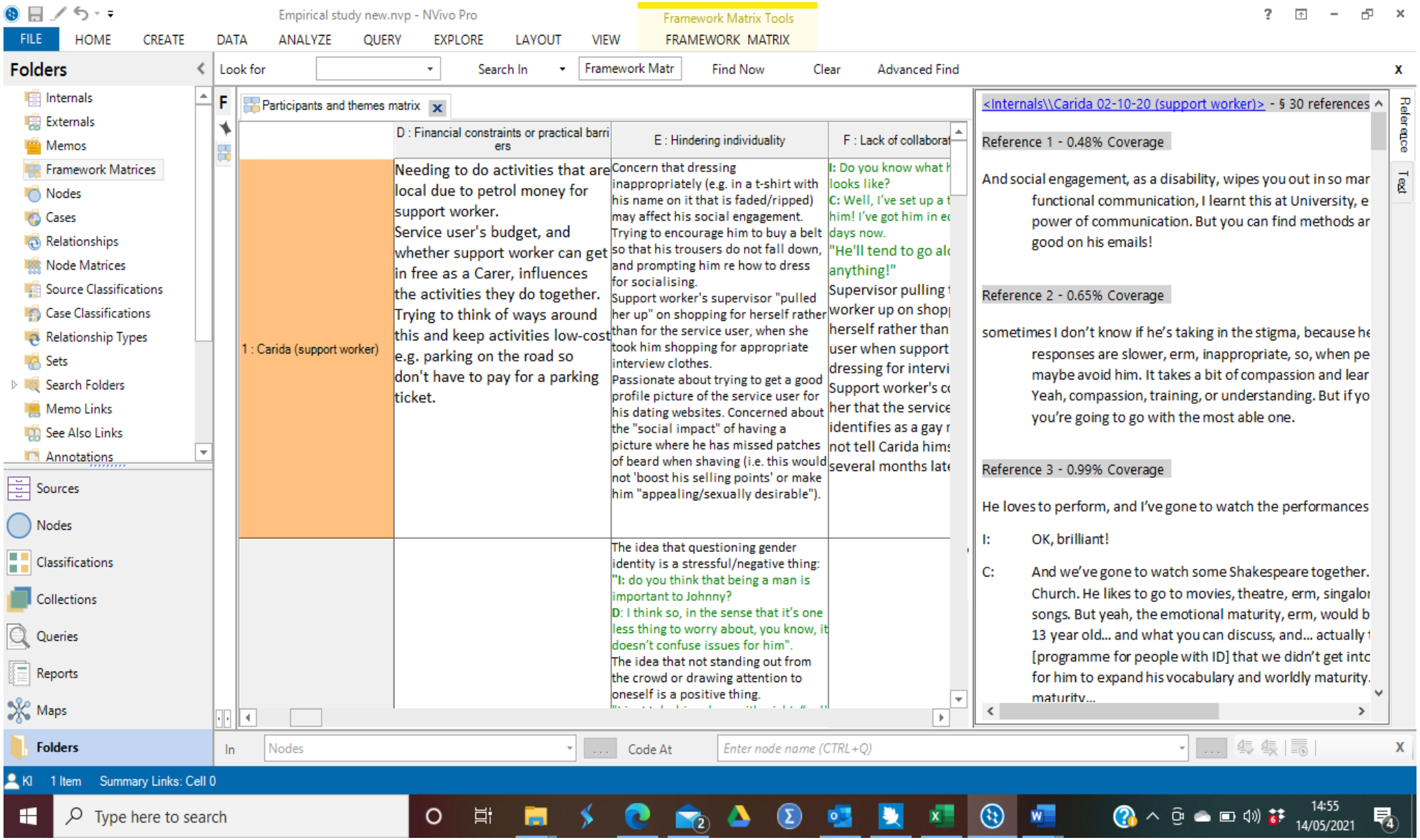
Repeatedly emphasising that Luke is very active. Sense that support worker is less passionate about this?

Lockdown negatively impacting on Luke's activities.

Luke has lots of different people around him in his support network.

Support with practical daily living skills	I:	OK great. And does he have support with things like household chores at home?	Luke lives in supported living with staff available 24/7. Definitely needs prompting with household chores.
	R:	Yeah so in his supported living home they have someone in there 24/7 and they're always, they all cook together erm and yeah they're just on hand for kind of day to day support, and even through the night as well. But yeah, he definitely needs prompting on, you know, they have rotas and stuff, and they'll check in and ask you know "Have you done this today? Have you done that today? Have you cleaned today? When are you doing this?" Erm…	
	I:	OK, that's really helpful, thank you. And, do you think that erm Luke's culture influences the type of activities that he likes doing?	
Sense of service user's lack of autonomy / acquiescence / not making own decisions?	R:	Erm [*pauses*] I guess so, I'm not really sure how he's kind of got into what he's got into as well... And who's made that kind of connection *for* him, erm, you know with the sports stuff. It's good that someone has! Whether it was his sister or it was his Mum at the time when he was younger maybe. Erm, but yeah he's very much – sport is his thing, and being active is his thing. Erm, but yeah it's interesting, I'm not sure what connection he's made there or who's made that connection for him… but it's not as though he's into something and he's doing it but he's not really sure why, or not sure whether he gets enjoyment out of it. He definitely loves what he does.	Assumes that someone close to Luke has encouraged him to get into sport. Sense that Luke does not often make his own decisions? Repetition of "is his thing". Definitely really enjoys sport and being active. Unsure of the history of this interest/how it developed. Perhaps defending Luke: even though he may not have decided this himself, he is now pursuing this interest because he genuinely likes it.
Service user is passionate about sport/being active	I:	Mmm, yeah. And do you know what kind of places he likes going to?	
Importance of belonging to a group/ connection/ acceptance. Enjoys bumping into people (perhaps because less likely to meet up with people in an organised or deliberate way? Has to happen by chance?)	R:	Erm again it's probably the stadium for [local rugby club], erm, he likes socialising – when he could do he was at the pub once a week maybe. He likes being out in Town because he bumps into people he knows. Erm, and just being around his family, I think. I get the impression that – he's never mentioned that he's lonely, but erm… he's on his phone quite a lot as well and he does a lot of kind of voice messages and he's constantly kind of like in contact and chatting to people, and that's how we kind of communicate now.	Sense that Luke's social life is intertwined with the rugby club. Enjoys being around and in contact with people. Concern that he may be lonely, although he has not expressed this explicitly. Perhaps something that is difficult/painful for Robert to consider, so he moves on quickly to say he keeps in touch with people a lot using his phone.
	I:	Oh really! You communicate through voicenote?	
Lack of social circle / peers – impact on identity?	R:	Yeah!	
	I:	Aw OK, and do you know who else he chats to by voicenote? Is it just his family, or anyone else?	Does not have many friends.
	R:	Yeah just his family, yeah. He doesn't seem to have a lot of friends. Erm, I think he's quite wary of people that he	

Appendix K: Extract from the NVivo Framework Matrix



Appendix L: Respondent Validation Themes

'What Being a Man Means to Me'
PROJECT THEMES

Understanding gender

- Men and women are different. They have different body parts.
- But men and women can do the same activities.

"boys can also enjoy ballet if they choose to do it"

- I like being a man.
- Being a man means being helpful and being strong.

Things I like about my support

- I do not mind if my support worker is a man or a woman.
- The most important thing is to feel comfortable with my support worker.

I don't mind the gender at all! Honestly, don't mind at all. If they're up for a good laugh and a giggle, then I don't mind the gender.

I don't know why I enjoy it, but I just enjoy being around people, no matter what gender they are …….. I just enjoy being around people.

- Spending time with people I like is more important than doing an activity.

What is good about time with your support worker?

Just spending a lot of time together with her. That I like.

- I like to be supported to make my own decisions.

<u>Things that can be difficult with my support</u>

	- It can be hard to know who to talk to about private things.
	**THANK YOU FOR YOUR TIME** Do you have things to say about the project findings on this sheet? Please tell your support worker if you would like Katie Ireland (the researcher) to arrange a meeting with you if you have things to say.

Appendix M: Themes, Subthemes and Contributing Participants

Theme		Subtheme	Contributing participants									
			Johnny[1]	Donald[2]	Thomas[1]	Carida[2]	Noah[1]	Emily[2]	Matthew[1]	Sally[2]	Luke[1]	Robert[2]
Understanding of gender and identity		Compartmentalised view of men and women	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		The meaning of masculinity	✓	✓	✓		✓	✓	✓	✓	✓	✓
		Contrast between masculine identity and ID identity		✓	✓	✓	✓	✓	✓	✓	✓	✓
Facilitating factors to developing gender identity		Trust, familiarity, and understanding		✓		✓	✓	✓	✓	✓		✓
		Support with social/emotional skills (not just practical)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		Support preferences	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		Promoting independence	✓	✓	✓	✓		✓	✓	✓	✓	✓
		Promoting individuality		✓		✓	✓	✓		✓		✓
Barriers to support with		Trust			✓	✓	✓	✓	✓	✓		

[1] Service user
[2] Support worker

developing gender identity		Practical barriers		✓	✓	✓	✓	✓				✓
		Lack of gendered support		✓	✓	✓		✓				
		Barriers to independence and individuality		✓	✓	✓	✓		✓			✓

Appendix N: Reflective Log Extract

18/09/2020

I was struck by the theme of infantilisation and overprotection in the first support worker interview. For example, the support worker said "he knows where he stands" in relation to the service user knowing that he should not go "too far" sexually with his girlfriend. He also commented that the service user was "sensible" in not focusing on getting married and having children (like his girlfriend was). I felt compassionate towards the support worker …. He viewed the service user as a younger brother and felt protective of him. However, I felt that despite these good intentions there was an assumption that the service user should not aspire to achieve these adult roles in his life. I also wondered whether the support worker's age impacted his perception of gender identity (perhaps an assumption of my own about older generations having less liberal views). He often spoke about sexuality and gender identity interchangeably and appeared to be quite concrete and perhaps old fashioned in his views ("nowadays you can be whatever you want"). I got the sense that my own values may have clashed with the support worker's at times.

08/01/2021

When coding the interview transcripts of the second dyad I noticed that my dubiousness around the support worker's actions was causing me to hold on to some double standards. For example, in other interviews with support workers I was impressed by their commitment to helping service users progress and develop new skills. However, with this particular support worker I saw it as overbearing and felt that she was not giving the service user enough space to develop his individuality. I tried to be aware of this disparity in my own judgement when analysing the transcript, in order not to let it impact how I was making sense of what the support worker was saying. I tried to be aware of my assumptions and think about another way to make sense of this. For example, "We went for lots of job interviews, and I had to cover up my knockbacks" also demonstrates how invested the support worker was in a good outcome for the service user.

27/11/2020

I noticed before doing today's interview that I was feeling quite exhausted and burnt-out, which caused me to worry afterwards about whether I had missed important leads to follow. I really warmed to this support worker and really admired the relationship he had with the young man he supports. However, although he appeared very kind and gentle the support worker had quite an expressionless face. I know that as a person I find it hard to continue a conversation when I am not receiving lots of positive feedback from the other person (such as when I have been interviewed for jobs!) I therefore worried that this caused me to pause and think and use silence less than I should have done. Also, I had already interviewed the service user previously, and he had the most severe communication difficulties of the participants. I therefore felt slightly anxious about whether I had always understood the essence of what he was saying. During today's interview with his support worker, I was aware of this and

was perhaps trying to clarify my understanding of the service user's character and opinions through the answers the support worker was giving. Once I noticed myself thinking about this, I strove to bracket this off and maintain a neutral stance.

The support worker also spoke about the service user's experience of being molested and bullied. I noticed a pull in me to stay on these topics for longer than would have been helpful or necessary in terms of the research questions. I felt insensitive and guilty when I moved on to other questions (despite knowing that this was not the main topic of the interview). This may have been me experiencing a clash between my usual clinical role and my role as a researcher. However, I can also find sticking to an agenda challenging at times in my clinical work.

Appendix O: Additional Illustrative Quotes

Theme	Subtheme	Additional quotes (service users)	Additional quotes (support workers)
Theme 1: Understanding of gender and identity	***Subtheme 1: Compartmentalised view of men and women***	Interviewer: what else do men wear? Luke: Erm, erm, erm, it's like normal clothes. Interviewer: And what do normal clothes look like? Luke: Erm, erm, erm, it's all Gym King. Interviewer: Gym King? Luke: Yeah. Interviewer: Is that a type of clothes? Like a make of clothes? Luke: Yeah. Interviewer: Ahh OK. And what type of clothes do you think that women normally wear? Luke: Erm, it's bra and knickers. *[Both laughing]* Something like that!	"yeah I think he's very aware of males and females and erm the differences and being gay and straight – he's happy to talk about any of that. He's got friends that are female and like other females… he's got friends who are surrounded by heterosexual couples and… he's kind of, he's… he's been around *everything*, he's not, nothing shocks him. And he's perfectly happy around everyone, and as long as people are happy, he doesn't care. He's not phased by anything, he's not drawn to one particular group of people, he's not – I dunno." (Emily) Interviewer: And what do you think his understanding of gender identity is? Robert: Erm I think it's probably more a physical thing, erm, being able to identify who is a man and who is a woman, certainly, I'm not sure it would go any deeper than that…
	Subtheme 2: The meaning of masculinity	Interviewer: Does Robert support you with manly things? Luke: Yeah Interviewer: What manly things does he support you with? Luke: Erm, everything hard Interviewer: Everything hard? Luke: Yeah.	"even when he goes to work, you know, it's like he's proud of the fact that he's gone to work, you know, that's something that's important for him" (Sally)

		Interviewer: What kind of hard things does he help you with? Luke: Erm, erm, I am fixing cars.	
	Subtheme 3: Contrast between masculine identity and ID identity	Noah: I've never been a big fan of sports. I've always been conscious of my weight. During school it wasn't pleasant to play sports. I: Ahh OK, it wasn't pleasant to play sports at school… and was that because of your weight? Did you say? Noah: Probably, and my social ranking in school and stuff. I wasn't a sporty child at all. The other sporty kids were way more sporty than I was. I: Ah OK, so you didn't really want to play with them? Noah: No. Not at all.	"it's erm like you know, when he goes to the pub, and he'll go on his own and I'll say you know do you want anybody to go with you? (This was when we first started supporting him) and he says "no it's OK I can go on me own" and erm so, yeah… but you know with Matthew, he's vulnerable too, he's *vulnerable*, you know and he *knows* that, to his level and way of understanding the vulnerability he's got, you know." (Sally)
Theme 2: Facilitating factors to developing gender identity	***Subtheme 1: Trust, familiarity and understanding***	Interviewer: So you said you had a good chat – what kind of things did you chat about? Matthew: What stuff I like and what I like doing.	"It's to listen, to talk to him… because I suppose sometimes it's difficult, you know, men find it hard to talk but I've noticed with Matthew that once you've got there as long as you listen to what he's saying and then you build up the conversation… and how I picture that, it's like when you've got an onion and you peel away the layers, well that's what happens in the conversation with him. And then we'll say, "Are you getting few up now?" and he'll sort of say "yeah" [*said shyly*], and that's when you know to stop." (Sally)
	Subtheme 2: Support with social/emotional	Interviewer: you said before that Carida supports you with things like applications, CVs and organising activities… is there	"the *work* to advance that side of yourself, erm, his social skill area, which are more advanced… and, the working skill area I can do prompt cards and things like that, they're more black and white and rigid, the job to

	skills (not just practical)		anything else that she supports you with?	be done, but I still have things what he can and can't say to work colleagues, and not to spend time chatting with people and more on-task… but those are more, I can get round those with rigid black and white, but erm, love is so expansive" (Carida) "they'd kind of not had, in my opinion, not has as much freedom when they lived with their parents as they would on their own. So it was all very new, and there were a lot of activities that were happening" … "and he didn't want to just stick with his housemates but then he didn't want to offend them, …….. And it was about explaining to Noah that that's absolutely fine – just because you live with these people doesn't mean you have to be with them all the time or do what they want to do. So it was kind of getting him used to that and settling him into that a bit more…" (Emily)
		Thomas:	Erm, sometimes with relationships, because I sometimes get a bit upset about what other people say sometimes… Like someone says something to me that's not quite true it makes me a bit upset and a bit angry and confused and that…	
		Interviewer:	Did you say angry and confused?	
		Thomas:	Yeah, sometimes I get the wrong sort of concept	
		Interviewer:	OK, yeah. And how does Carida help you with that?	
		Thomas:	Overcome it and just ignore it really.	
	Subtheme 3: Support preferences	Interviewer:	Do you like to have support from a man or a woman? What is better?	
		Luke:	Erm, I like both.	
		Interviewer:	Both, yeah! And why do you say both?	
		Luke:	Erm, it's like I have a good time together	
		Interviewer:	And, do you prefer to have support from a man or a woman?	
		Matthew:	Both.	
		Interviewer:	Both. Can you tell me more about why you say that?	
		Matthew:	They'll understand what I'm talking about and what I need support with.	

		Interviewer: OK, so, do you mean that it doesn't matter if they are a man or a woman, just that they understand what you Need support with? Matthew: Yep.	
	Subtheme 4: Promoting independence	Interviewer: and what sort of places do you like to go to? Johnny: Err… oh, erm, go to museums, aquariums, sea Life centre in Brighton, all sorts of different places. Interviewer: OK great, and who normally decides the places you go to? Johnny: I think it's mostly myself.	"Yeah, I mean we'll make some suggestions like so and so is free, did you want to go and see what films are on, did you want to go for a walk, do you want to see if the gaming shop's open or – things we know he'll enjoy. And then he just decides what he wants to do." (Emily)
	Subtheme 5: Promoting individuality		"you know there are things that, you know, that you see that is more, but it's *very* minute, but there are things that he likes that he'll point out to you that he does like things that more of a woman would like. But it's no different from a woman's point of view. Like I've said to him, I said, "I like masculine things! It's that balance! There's no right or wrong!" I said, "Whatever *you* like, if you're, if you like a certain thing, whether it's feminine or masculine, you just have it!" [*exclaims emphatically/speaking quickly*] So, you know… But clothes-wise, yeah more, without a shadow of doubt, that's more masculine." (Sally)
Theme 3: Barriers to support with developing gender identity	***Subtheme 1: Trust***	Interviewer: would you like your support to be different at all? Thomas: Yeah, a little bit. Interviewer: Can you tell me more about that?	Emily: With Noah it's really about getting to know him first... Some of his jokes are still there and he'll be a little bit cheeky, um, and a little bit risqué, but he wouldn't… he wouldn't be as comfortable, like, as he would if Sam or

		Thomas: Erm, maybe not some of the information about me, as such, being sent to other people… Interviewer: Can you tell me more? Thomas: When she writes to my other support worker, yesterday, I think, she wrote her a long message and I didn't think it was very necessary to do that, to be honest.	I were there because he knows us really well. Interviewer: Yeah, so it's more about how well he knows you, not whether the person is male or female. Emily: I mean, from my experience I've seen it all and heard it all with Noah, so I don't think it's a gender thing [*laughs*]
	Subtheme 2: Practical barriers	Interviewer: And, would you like to do different things with Emily? Noah: I don't know what else we can do with Emily! There's nothing really around here in walking distance that you can do, that doesn't cost money. Interviewer: OK, so it would need to be free really would it? Noah: Yeah free, or really cheap to go into.	"and obviously he has a set allowance for doing stuff, so then there's that limitation of you know we can't get on a train to Manchester and go and have a, I dunno, go and watch Man United Match of the Day or something like that" (Robert)
	Subtheme 3: Lack of gendered support		"Yeah, in, I sort of mentioned that there aren't *too* many men that work in disabilities, like this, so they're fewer on the ground anyway, but in [support service] there are some. I mentioned David in employability, and it was nice that erm David helped me erm, so, even David puts his clothes out and gets him ready… things like shaving as well, that he misses, sometimes there are like big tufts of beard that he misses, I think he does it really quickly, or… I did mention his brother the other day! Cause, I think he said he might get his brother to do it" (Carida)

			"a lot of the people in charge of the groups would be women. And so they would put the activities together" (Donald)
	Subtheme 4: Barriers to independence and individuality		"He'll tend to go along with anything!" (Carida) Interviewer: Do you know what his usual day looks like? Carida: Well, I've set up a timetable for him! I've got him in education a lot of days now.

Appendix P: Clinical Implications Table (to be sent to participating services with the lay summary)

Study finding	Key recommendation for services
A sense of belonging and building trust	
Service users value a sense of belonging and connecting with others highly. However, services prioritise support with practical skills.	A change in the culture of ID services is needed. Services should be like a community, so that service users feel that they belong. Increased support with forming and maintaining relationships is needed. Organisations such as Supported Loving and Bild have developed guidance on supporting people with ID to develop and maintain friendships (Choice Support | Making friends / Friends and Relationships | bild). The Gig Buddies initiative (https://gigbuddies.org.uk/) matches people with ID with volunteers with similar interests and passions. This increases service users' social circles and confidence in socialising.
Trusting relationships between staff and service users is needed for support with developing identity. Services focus on support with practical skills. This means less one-to-one leisure time with service users and less opportunity to build trust.	Again, a change in the values and priorities of ID services is needed. There should be a focus on developing the connection between staff and service users. Commissioners and service managers need to allocate resources appropriately, so that support workers can spend time providing social/emotional support as well as practical support.
Service users are likely to need encouragement to talk about their likes, dislikes, and interests. Support workers need to actively try	Staff training is needed so that support workers feel more confident to have sensitive conversations with service users.

to start these meaningful conversations with service users. This will help service users to develop their identities. However, staff lack opportunities for starting these conversations because of the focus on support with practical skills. Staff also lack confidence in having these conversations because they are concerned about service users' privacy. Service users also said they can find it difficult to open up to staff. They can be worried about information being shared in staff handovers.	Specialist supervision and consultation from Psychological services could be helpful. Mencap have developed helpful resources for conversations about gender identity and individuality with people with ID (including a video discussion around You Being You Relationships and sex resources | Mencap). Supported Loving have guidance on writing a sex and relationships policy in order that staff feel confident to address these issues (Choice Support | Writing a sex and relationships policy) Services may need to update their guidance around information sharing, to include the need to discuss this openly with service users. People with ID should be supported to understand the pros and cons of sharing information in handovers.
Tackling stigma	
Society can be focused on seeing service users as intellectually disabled. This can mean that service users are not seen and treated as "real" men and women.	Service managers should introduce reflective practice sessions for staff. This may help staff to be aware of when they are focusing on intellectual disability rather than service users' individual identities. Bild provide training on awareness of what it means to have a learning disability, including how the public perception of people with learning disabilities can create barriers to inclusion (All about us and our lives: valuing people with learning disabilities and autism | bild).

The stigma around ID can prevent service users from exploring their individuality as they are focused on "fitting in".	Service managers should introduce LGBTQ support groups and education groups for service users or identify where these groups already exist and support service users to access them. Support workers should be trained in having open conversations about disability with service users to address any misinformation and tackle stigma. UCL are conducting research and relevant projects to tackle intellectual disability stigma (Research on Intellectual Disability Stigma | UCL Psychology and Language Sciences - UCL – University College London). For example, the STORM project supports people with ID to cope with and stand up to stigma. The Supported Loving organisation have developed a toolkit on promoting diversity and inclusivity when working with people with ID (Choice Support | LGBTQ+)
People with ID see themselves very differently to how society perceives them. This can be damaging for their self-identity.	Support workers should be trained in how to support people in a way that truly appreciates them as a person beyond their ID diagnosis (Example: Training - what we can help you with - Stay Up Late).
Promoting independence	
It is important that independence is prioritised and encouraged among men with ID.	Service managers must be vigilant to acquiescence among people with ID. They must help people with ID feel able to speak for themselves. Increased advocacy services and self-advocacy groups are likely to be helpful for this. (Example: the People

	First organisation supports self-advocacy groups across the country: People First (Self Advocacy) - we are 336) The Foundation for People with Learning Disabilities run projects focused on connecting service users with their communities in order to improve quality of life and enable people to lead more independent lives (Community Connecting | Foundation for People with Learning Disabilities)
Service users need to have more control over their lives and care, including: 1) being presented with meaningful choices around activities, 2) having the ability to choose between staff members, 3) being supported to make their own decisions about their everyday lives.	Service managers should strive to boost the recruitment of men to ID services. Services should organise training in how to meaningfully involve people with ID in the process of staff recruitment. (Training - what we can help you with - Stay Up Late). Services must adopt Person Centred Planning (Person-centred planning (PCP) | Foundation for People with Learning Disabilities). Service users must be involved in day-to-day decisions about their lives. Accessible information must be provided to support decision-making. Helping people with ID to grow their social circles and do a variety of activities has been shown to increase service users' confidence in decision-making. (For example: (https://gigbuddies.org.uk/) Services must ensure that support matches the lifestyle that people with

	ID really want. ID services should have a formal process for receiving regular and ongoing service user feedback. The Stay Up Late charity can advise on setting up service user advisory groups (Training - what we can help you with - Stay Up Late). ID service teams need specialist training in how to support people with ID in a way that is truly led by them (Example: Training - what we can help you with - Stay Up Late). The Foundation for People with Learning Disabilities was commissioned by Health Education England to find out what people with ID want from those who support them (Workforce development for people with intellectual disabilities | Foundation for People with Learning Disabilities)